

# **Access to Employment Opportunities for People with Spinal Cord Injuries**

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## ABSTRACT

Traumatic spinal cord injuries (SCI) instantaneously transform people's lives from a state of active physical well-being to one of total or partial paralysis. One of the most profound changes experienced by people who sustain SCI is a loss of choice and narrowing of options in all aspects of life, including employment opportunities. Improved survival rates of people sustaining SCI and fewer medical complications has meant that the issue of return to work has become an important consideration in the rehabilitation process. The provision of appropriate vocational rehabilitation and support services can enhance people's ability to gain and maintain employment after their SCI. This study looks at employment issues for people with SCI within the New Zealand context, which is different to other countries primarily because of the accident compensation system. This research is based on in-depth interviews with seventy spinal cord injured people from all over New Zealand that have been at the Burwood Spinal Injuries Unit for reassessment or further medical treatment. This study establishes the rate and nature of employment of the participants, and identifies factors, which affect employment outcomes for this group of people, including the timeliness of vocational rehabilitation. It also explores some of the life changes of SCI and the impact of the groups' employment outcomes on their perceived health status, social outcomes and life satisfaction.

*Key Words:* spinal cord injury, disability, vocational rehabilitation, employment.

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## LIST OF ACRONYMS AND ABBREVIATIONS

ACC	Accident Compensation Corporation
ACS	Accident Compensation Scheme
ADL	Activities of daily living
ARCIC	Accident Rehabilitation and Compensation Insurance Corporation
CNS	Central Nervous System
DSS	Disability Support Services
DPA	Disabled Persons Assembly
ERC	Earnings Related Compensation
FES	Functional Electrical Stimulation
HFA	Health Funding Authority
ICIDH	International Classification of Impairment, Disability and Handicap
NACEW	National Advisory Council on Employment of Women
NZSCO	New Zealand Standard Classifications of Occupations
OT	Occupational Therapist
RHA	Regional Health Authority
SCI	Spinal cord injury
SES	Socio-economic status
SIA	Spinal Injuries Association (Britain)
SIU	Spinal Injury Unit
WHO	World Health Organisation
WINZ	Work and Income New Zealand

## CHAPTER ONE: Introduction

### 1.1 Background

"... disability can happen to anyone. Overnight we become strange, alien, *different*, as far as the able-bodied world is concerned - we stick out a sore thumb in most public places, whereas before our injury we would have passed unnoticed." (Morris, 1989: 14)

There is an emerging interest in disability within human geography (Smith, 1999). Despite a longstanding interest of geographers in health and health care there has been a lack of geographic literature on disability issues. This has tended to reflect the absence of people with disabilities in academia, and, also their relative powerlessness in society (Chouinard & Grant, 1995; Imrie, 1996a). However, the number of disabled people working in the open labour market and studying in academia is increasing, and more books are now being published on disability issues as a consequence (Shakespeare, 1998). The increasing assertiveness among the disabled population has been attributed to the rising number of people who are acquiring disabilities as adults (Smith, 1999; Tennant, 1996). The profile of disability issues has also been raised with the proliferation of advocate and self help groups, as disabled people have begun to organise themselves (rather than being dominated by professionals) and push for a consumer voice in decision making (Barnes, 1998).

People with disabilities include a wide range of physical, sensory and psychiatric, learning and developmental disabilities (Ratima et al, 1995). This study however, focuses specifically on injuries to the spinal cord, which frequently result in profound physical disability. As the opening quote by Morris (1989) clearly describes, traumatic spinal cord injuries instantaneously transform individual's lives from a state of active physical well being to one of total or partial paralysis. Whatever the cause, paraplegia or tetraplegia has a devastating impact on the person concerned and their family and friends (Sherrard, 1996). People with

spinal cord injuries (SCI) have to cope with profound physical and emotional changes, and with a new and different way of life in a world designed for able-bodied people. It is important to acknowledge that the effects of SCI vary greatly depending on the type and level of injury (see Appendix A and B for specific details and definitions regarding spinal cord injuries). It is also difficult to generalise and suggest how well people who sustain SCI adjust to their new way of life, as the process of rehabilitation is continual and ongoing (Craig et al, 1994b; Smaill, 1982; Minchington & Julian, 1989).

One of the most profound changes experienced by people who sustain spinal cord injuries is a loss of choice, or a reduction of options in all aspects of life such as employment, housing, transport, holidays, leisure and recreation. This thesis examines the employment experiences of people with SCI in New Zealand. Research suggests people with physical disabilities are more likely to be excluded from the labour market and be unemployed for longer periods, than able-bodied people. People who have developed spinal cord impairments (due to injury, medical conditions or illnesses) may not be able to resume their previous occupations for a variety of reasons. Generally, when physically disabled people are employed they tend to be relegated to low paid and unskilled occupations (Imrie, 1996b; Kestenbaum, 1996; Simpkins, 1994; Studholme, 1994; Oliver, 1996).

This chapter will begin by describing the history of treatment and medical knowledge on spinal cord injuries before looking at the issues of return to work after SCI. It will then describe the specific objectives of this study and it will conclude by outlining the overall structure of this thesis.

## **1.2 The History of Treatment and Medical Knowledge on SCI**

SCI can result from either traumatic or non-traumatic injury. Non-traumatic injuries can be caused by illnesses (such as tumours or abscesses of the spinal cord) or medical conditions

(for example, Spina Bifida, Multiple Sclerosis and Poliomyelitis) which can be congenital or acquired. The loss of function does not differ whether the damage to the spinal cord is traumatic or non-traumatic. Damage to the spinal cord may however, be gradual if it is due a medical condition or illness (Parker, 1996; Spinal Cord Injury Resource Center, no date).

Prior to World War II, no major advances had been made in the care of spinal injuries and the injury was considered terminal (Gidlow, 1977). People who sustained SCI usually died within weeks of their injury due to medical complications such as bladder and kidney problems due to urinary tract infections associated with incontinence, skin problems including pressure sores, respiratory problems, and pneumonia (Corbet et al, 1998; Maddox, 1990). John Young, a renowned SCI doctor, noted that the subject of rehabilitation seldom came up before World War II:

“...any attempt to restore such persons to their former activities seemed out of the question and the view generally held was that the sooner he died the better for all concerned.” (Quoted in Maddox, 1990: 23)

People with spinal cord injuries were normally scattered among general medical wards or surgical wards, from which they were eventually transferred to “chronic wards” or “homes for incurables”. But the work of Guttmann, in the 1940s in Britain and Munro, in the 1930s in the United States, initiated a fundamentally new approach to SCI care by creating units that were dedicated to treating paralysis as a specialised medical problem (Maddox, 1990). During World War II, twelve of these specialised SCI units were set up. People were concerned that the air raids would injure large numbers of civilians in addition to soldiers. The British hoped that centralising the care of SCI cases would allow paraplegics and tetraplegics to be systematically studied to enable more effective treatment and rehabilitation for people with SCI (Corbet et al, 1998; Maddox, 1990).

Sir Ludwig Guttmann pioneered the “total person approach” to SCI treatment and rehabilitation. It was recognised that people who sustained SCI could only receive the fastidious care that they needed if medical staff could solely focus on the treatment of spinal cord injuries and their associated problems. Staff teamwork became a vital part of SCI care (Maddox, 1990). Guttmann’s work at Stoke Mandeville Hospital, in England and the knowledge acquired there was disseminated around the world. Stoke Mandeville Hospital was eventually designated as Britain’s National Spinal Injuries Centre and it became a model for many other countries including Japan, South Africa, Australia and New Zealand. Consequently, the life expectancy of people with spinal cord injuries significantly improved (Corbet et al, 1998; Gidlow, 1977; Maddox, 1990).

Significant advancements were made in medical and psychosocial areas and the myths surrounding SCI were also challenged. Guttmann recognised that pressure sores and bladder infections were not a natural, inevitable consequence of a spinal injury. He endeavoured to:

“rescue these men and women from the human scrap heap and to return most of them, in spite of their profound disability, to the community as useful and respected citizens. The chief object was not to just preserve the lives of paraplegics and tetraplegics... but to give them a purpose in life... Naturally the practical application of this philosophy was no simple task, considering the thousands of years’ old prejudice towards spinal cord sufferers.” (Quoted in Corbet et al, 1998: 62)

Guttmann’s team was the first to replace the continuous drainage of the paralysed bladder with intermittent catheterisation. The Guttmann era also saw the development of wheelchair sports, vocational rehabilitation, and special equipment to give people with SCI greater independence. British health authorities became convinced that people with spinal cord injuries could contribute to society despite their physical disability (Corbet et al, 1998; Maddox, 1990). This helped to broaden the opportunities for people with SCI to participate in a variety of productive activities including paid employment.



In the 1950s the United States “model system” approach for SCI care and rehabilitation was developed, to meet the acute and lifetime medical needs of people with SCI by establishing centralised, comprehensive and multi-disciplinary facilities. Dr. Donald Munro, a neurosurgeon, is recognised for establishing the first spinal injury unit for civilians consisting of ten beds, at the Boston University Hospital, in the 1930s. Both Munro and Guttman acted as role models for Dr. John Young, who in 1956 developed the first American complete care spinal injury system at Craig Hospital in Denver, Colorado (Corbet et al, 1998).

The improvement in medical knowledge and technology has dramatically improved the survival chances of people with SCI (Tennant, 1996). The advent of modern antibiotics and materials such as plastics and latex, and improved procedures for dealing with the everyday issues of living with SCI, has meant that the life expectancy of many people with SCI now approaches that of non-disabled individuals (Spinal Cord Injury Resource Center, no date). Kidney failure used to be the primary cause of death for people with SCI. But improved urological management means that people with SCI are now more likely to die of the diseases the non-disabled population dies of, for example, heart disease or cancer (Corbet et al, 1998; Maddox, 1990).

Currently, there is no cure available for SCI and damage to the spinal cord is irreparable and permanent (Sherrard, 1996). However, there are a number of treatments and technological devices available now which can improve the function, independence and quality of life for people with SCI such as tendon transfers, Brindley implants and FES (Functional Electrical Stimulation) devices. The drug methylprednisolone is a major advance in spinal cord research if it is administered in high doses within eight hours of injury. Research has shown that it reduces swelling of the spinal cord and can save twenty percent more neurons than if the drug is not used. For some people with SCI this could mean the difference between using

a wheelchair and walking (Burwood Hospital, 1998; Rosenblatt, 1996; Spinal Cord Injury Resource Center, no date). Methylprednisolone is now regularly prescribed in many countries including New Zealand (Hirst, 1999).

Christopher Reeve, the American actor made famous by playing the role of Superman, is politically active in promoting awareness and research to find a cure for SCI. Reeve was thrown from a horse in 1995 and injured his spinal cord between the first and second vertebrae (see, Appendix B). This left him paralysed from the neck down and dependent on a ventilator to breathe (Rosenblatt, 1996). In 1996, he established the Christopher Reeve Foundation, which subsequently merged with the American Paralysis Association in April 1999, to form the Christopher Reeve Paralysis Foundation. Together they are fundraising for medical research leading to the development of effective treatments and ultimately a cure for paralysis caused by SCI (see, [www.apacure.com/crf.html](http://www.apacure.com/crf.html)). The Internet provides some of the latest information on research into finding a cure for SCI (see, for example, [www.cureparalysis.org/](http://www.cureparalysis.org/)). Scientists are currently looking at spinal cord regeneration and repair. They are trying to work out why the central nervous system (CNS) does not regenerate when many other cells throughout the human body can (Corbet et al, 1998). There have been some encouraging results with paralysed rats regaining function (Gorman, 1996; Rosenblatt, 1996).

### **1.3 Return to Work After Spinal Cord Injury**

Improved survival rates of people sustaining spinal cord injuries and fewer medical complications has meant that the issue of return to work has become an important consideration in the rehabilitation process (Murphy & Athanasou, 1994). Work is highly valued in our culture and it is often regarded as one of the most important social roles that

people have. It serves a variety of functions including providing financial security, challenges, social interaction and is a means of increasing self-esteem (Smith, 1997; Young et al, 1994; Berkowitz & Hill, 1986). The existing literature regarding employment after SCI details a diversity of return to work rates. Studies on employment after SCI often differ with respect to sampling procedures, sample characteristics (for example, age, level of injury and time of follow up since onset of injury), methodology and variations associated with employment outcomes (Krause and Anson, 1996). Some studies may be dated due to legislative, social and economic changes that can alter the conditions in which people with SCI look to obtain and retain employment (Crisp, 1990). The findings in the literature need to be interpreted within the context they are conducted as different countries have different employment possibilities and benefit systems. Murphy and Athanasou (1994: 51) suggest that "The variability in study results indicate that further evidence is required to describe more reliably the nature and extent of employment or return to work". Furthermore, Krause (1992: 164) suggests that:

... research is needed that focuses attention on individuals several years after injury, with widely varying ages and educational levels. This research would help to clarify the inconsistencies in past studies that determine one employment rate for an entire sample, and would help to identify subgroups of individuals with SCI who may need special services or who experience special problems.

Previous studies have often tried to explain vocational outcomes in terms of characteristics of individuals with SCI and have given little attention to environmental variables such as employer attitudes, rehabilitation methods and financial disincentives to employment (Crisp, 1990). Overseas studies conducted in the United States and the United Kingdom have shown that younger people are more likely to return to work than older people; paraplegics are more likely to return to work than tetraplegics; and those with a high level of education are more likely to return to work than those with a low level of education (Castle, 1994; De Vivo et al, 1987; Lindemann, 1981; Ville & Ravaud, 1996). Some other variables that have been identified as affecting

employment after SCI include: pre-injury employment experience, gender, job seeking effort, marital status, geographic situation with more job opportunities in urban areas than in rural areas, motivation to work, transportation, presence of other injuries, psychological adjustment, rehabilitation services, support from family and friends, and medical problems such as bowel and bladder care (Murphy & Athanasou, 1994, Burnham et al, 1996; Lindemann, 1981).

## **1.4 Specific Research Objectives**

There has been general research on disability and employment (for overseas research, see, for example, Barnes et al, 1998; Berkowitz & Hill, 1986; Croxen, 1984; Dench et al, 1996; Leonard, 1986, Murray, 1996; North, 1984 and for New Zealand research see, for example, Disability Sector Vocational Coalition, 1997; Gray & Neale, 1991; Johns, 1991, Lavery, 1996, Robinson, 1996, The Hillary Commission & Workbridge, 1994). Recently there have also been two conferences held in New Zealand, which have discussed disability and employment: the "Back to work - the future & the way ahead" conference held in Christchurch in 1997 and Rehabilitation International's 18<sup>th</sup> World Congress held in Auckland in 1996 that had 1400 delegates from eighty seven countries which focused on 'equality through participation'.

To the best of the researcher's knowledge this is the first New Zealand study to exclusively investigate the employment experiences of people with SCI. It looks at employment issues for people with SCI within the New Zealand context, which is different to other countries primarily because of the unique system of accident compensation, that is administered by the Accident Compensation Corporation (ACC). This study is based on an in-depth survey of seventy people with traumatic SCI at the Burwood Spinal Injury Unit (SIU), which is one of the two specialised SCI centres in New Zealand. The factors predicting a successful return to work for people with SCI in New Zealand have not been established. This research moves

beyond a simple description of people with spinal cord injuries or the general implications of urban design or public policy on accessibility, to encompass the experiences of people with SCI by incorporating the principles of the social model of disability.

The primary purposes of this study were:

1. To identify if there are any shortcomings in the current provision of vocational rehabilitation and support services for people with spinal cord injuries.
2. To establish the rate, type and predictors of employment for people with spinal cord injuries in New Zealand.
3. To explore some of the life changes after SCI and the impact of employment outcomes for people with spinal cord injuries on their perceived health status, social outcomes and life satisfaction.

This study hopes to improve understanding about spinal cord injuries and to recognise the abilities of people with SCI with regard to employment. It is hoped this study will be of use to the providers of rehabilitation and support services for people with SCI, including the Burwood SIU, ACC and Workbridge as well as being beneficial for people with SCI generally. This research will help give recognition to the needs of people with SCI and to the importance and necessity of introducing vocational rehabilitation early on in the rehabilitation process. It will attempt to make public the concerns and difficulties that people with SCI face, when returning to work and to illustrate the ways in which able-bodied people can 'dis-able' people with SCI both by their attitudes and the organisation of the physical environment.

## **1.5 Thesis Outline**

This chapter will conclude by outlining the overall structure of this thesis. The next chapter will show how at different times and in different places, disability was and still is, conceived

of in a variety of ways. It will examine the growing body of literature on the geographical perspectives of disability.

Chapter Three focuses on methodological research issues which includes recognising the strengths and weaknesses of the sampling methods used in this study. It then sets the scene by illustrating some of the demographic and injury related characteristics of the seventy participants with SCI in this study. The material is then organised into separate chapters dealing with vocational rehabilitation and employment following SCI.

The next two chapters examine the issue of vocational rehabilitation. Chapter Four concentrates on SCI rehabilitation. It specifically focuses on vocational rehabilitation within the hospital system at the Burwood Spinal Injuries Unit and discusses the timeliness of vocational rehabilitation within the rehabilitation process. Chapter Five provides an overview of disability in New Zealand and then looks at vocational rehabilitation and support services for people with SCI within the community once they are discharged from hospital. The history of accident compensation in New Zealand is explored and so is the establishment of Workbridge which is the specialist employment agency for people with disabilities.

Chapter Six describes the rate and nature of employment of the participants in this study at the time of their injury and at the time of the interview. It compares the findings of the current study with those from previous overseas studies on return to work following SCI. While it is appreciated that employment can occur on a voluntary unpaid basis, for the purposes of this study it is considered that the term *employment* will infer that a person is receiving an income whether it is for part-time or full-time employment. The factors affecting employment after a spinal cord injury are also discussed at length. The barriers to accessing employment opportunities for people with SCI are then examined in Chapter Seven. This is followed by an assessment of some of the life

changes after SCI and the impact of employment outcomes on perceived health status, social outcomes and life satisfaction in Chapter Eight

The final chapter revisits the objectives of this thesis. It summarises the main conclusions and limitations of this study. The practical implications of the findings are considered along with future research directions.

## **CHAPTER TWO:        Geography and Disability**

### **2.1    Introduction**

The previous chapter suggested that there is an emerging interest in disability in human geography. This chapter will show how disability was and still is, conceived of in quite diverse ways. It discusses the medical model and the social model of disability. Although the focus of the current study is on people with SCI when information has not been available specifically on SCI more general information on people with disabilities has been used. This chapter will also review some of the recent positivistic, interpretative and emancipatory research on physical disability within human geography.

### **2.2    Definitions of Disability**

This section discusses the recent developments and ongoing debates on the conceptualisation of disability, which have accompanied the growing disability rights movement. Smith (1999) suggests that the disability movement was developed and promoted by people with specific types of impairments who had acquired disabilities in adulthood and those who had impairments of an immutable nature namely blindness, cerebral palsy and paraplegia. Definitions of disability are dependent on the way in which a specific disability is perceived by society as a whole. The onset of industrialisation, with the separation of home and work, and the emergence of a philosophy that only those who were 'fit' for work were of value, was influential in transforming the social and economic status of many individuals with disabilities (Hahn, 1988; Gleeson, 1996; Barnes, 1998). Oliver (1990) has argued that the source of exclusion of people with disabilities resulted from the rise of capitalism with its emphasis upon individualism, achievement and independence. It is important to acknowledge that regardless of the definitions that are used that people with disabilities are not a

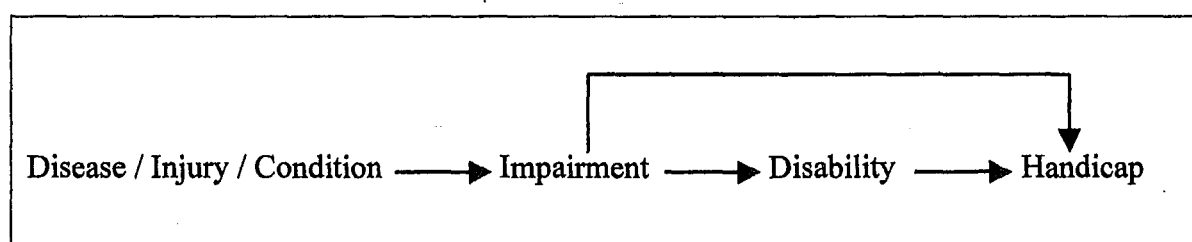


homogeneous group and their capabilities, needs and the barriers they face are not necessarily the same.

### 2.2.1 The World Health Organisation Classifications

The World Health Organisation (WHO) developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980. This was published in an attempt to standardise the conceptual framework and definitions of disablement. It makes the distinction between three possible consequences of health conditions namely impairment, disability and handicap (refer to Figure 2.1) (Katzehellenbogen, 1998). *Impairment* is described as any "loss or abnormality of psychological, physiological or anatomical structure or function" (WHO, 1980: 27). This definition relates to parts of the body that do not work. A *disability* is defined as "any restriction or lack of ability (resulting from an impairment) to perform an activity in a manner or within the range considered normal for a human being" (WHO, 1980: 28). In other words, this refers to things that someone cannot do or has difficulty doing. A *handicap* refers to a "disadvantage resulting from an impairment or a disability that limits or prevents a role that is normal (depending on age, sex, race and social or cultural factors) for that individual" (WHO, 1980: 29). This definition reflects the part that an individual can play in society and the kinds of relationships which they can enter into.

**Figure 2.1 The World Health Organisation process of disablement**



(Source: Katzehellenbogen, 1998: 12)

There have been concerns expressed about the medically based WHO classifications because they primarily focus on the individual and they attribute causation to the individual who lacks the ability to function in the surrounding environment (Studholme, 1994). Morris (1997) has criticised the WHO classifications for not recognising that two people with the same level of impairment may have different experiences depending on the attitudes, support and the environment which are a feature of their everyday lives. The WHO classifications have also been criticised by Oliver (1990) and Lawrence (1998) for not defining what is normal. A revised WHO classification is currently being developed to incorporate recognition of the importance of identifying both individual needs and the barriers in society encountered by people with disabilities (Katzehellenbogen, 1998).

### **2.2.2 The Medical Model of Disability**

The medical model has traditionally guided disability research. This locates the 'problem' of disability within the individual and sees the causes of this problem stemming from the functional limitations or psychological losses which are assumed to arise from disability (Hahn, 1997). According to the medical model, disabilities are seen as the property of individuals and they are best overcome by medical or rehabilitative treatments (Berthoud et al, 1993; Wight Felske, 1994; Imrie, 1996a; Oliver & Barnes, 1998). Imrie (1996b) suggests that the medical model implies an able-bodied/disabled dualism, which categorizes able-bodied as somehow 'superior' and 'more able' than disabled people. The dominance of the medical model reflects the power held by professionals in the disability field and the disempowerment of people with disabilities, who have opposed this conceptualisation of disability and its' implications (Ballard, 1994).

This model has been criticised for suggesting that people's impairments are ultimately responsible for the problems that they face and it fails to take account of the wider aspects of disablement

(Simpkins, 1994). Research based on the medical model has often been constructed in an oppressive way that does not allow people with disabilities to talk about the social, physical and attitudinal barriers caused by society (Imrie, 1996a).

### **2.2.3 The Social Model of Disability**

In a paradigm shift the medical model of disability has been rejected in favour of the social model. Consequently, the focus has shifted from the individual impairment to the disabling effects of the social organisation and structures designed around and for non-disabled people (Ward & Flynn, 1994; Welham, 1997). While the medical model was a product of exclusion, the social model was produced by demands for equal rights and inclusion into mainstream society (Smith, 1999).

The social model of disability argues that:

People who lack particular physical or mental abilities have been rendered 'disabled' by a society whose organisation marginalises them economically, politically, and socially and ignores their interests in the creation of the built environment (Butler & Bowlby, 1997: 412).

This model does not deny that people have medical needs. Instead it suggests that people are disabled by society which erects social and environmental barriers to their participation and independence. Society, therefore, fails to accommodate disabled people by not recognising their needs and providing appropriate services and support (Abberley, 1993; Hughes & Patterson, 1997; Oliver & Barnes, 1998; Oliver, 1996; Simpkins, 1994; Shakespeare, 1993; Swain et al, 1993). Disability is therefore seen as:

...something imposed on top of impairment by the way people with disabilities were excluded from the full participation of life, because of social attitudes and the physical limitations imposed by an inaccessible built environment (Smith, 1999: 52).

For example, the difficulty of travelling to work is a function of the design of transport systems and buildings and not the people trying to use them (Kestenbaum, 1996). Imrie

(1996a) suggests that when disabled people fail to obtain employment this is often linked to individual impairments rather than resulting from forms of social and political discrimination. Furthermore, Gant and Walford (1998: 245) recognise that:

...the daily difficulties encountered by mobility impaired people are not wholly related to health status, but prevailing attitudes in society, insensitive planning and the characteristics of local environments.

Research on disability conducted under this understanding can identify the places and social spaces in which disablement occurs.

Disabled people have enthusiastically identified with the social model because it related to their own experiences. However, the social model does not connect with the experiences of all people with disabilities. The explanatory power of the social model has also been questioned (Oliver, 1996; Morris, 1991; Watson, 1998) in that it may only partially explain the social 'oppression' of people with disabilities. According to Vernon (1998) the problem is not with the social model but rather how it is applied. She recognises that for the majority of disabled people their experience of oppression is shaped by other dimensions of their lives such as their sexuality, class, age and gender (see also Chouinard & Grant, 1997). It is important to recognise that 'oppression' is not always conscious and intentional. Young (1990: 41) suggests that oppression now refers to "the disadvantage and injustice some people suffer not because a tyrannical power coerces them", but because of:

often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms-in short, the normal processes of everyday life.

Thus the causes of oppression "are imbedded in unquestioned norms, habits and symbols, in the assumptions underlying institutional rules and the collective consequences of following those rules" (Young, 1990: 41). According to Young (1990) the unconscious actions of many individuals contributes to maintaining and reproducing oppression on a daily basis. However, such people may not see themselves as agents of oppression as they are usually simply doing

their jobs or living their lives. Morris (1991) in her book *Pride Against Prejudice* explores the experience of being different in the context of prejudice that is evoked by disability. It challenges the reality of being different by dismissing the myth that life for disabled people is "not worth living" and exposes cultural and institutional prejudice against disabled people.

The social restrictions imposed upon impaired individuals by society are themselves disabling. For people with SCI this view is somewhat inadequate because having a spinal cord injury imposes a number of personal problems such as incontinence, the risk of pressure sores and urinary tract infections, which can not be fully explained in terms of social oppression (Hoad et al, 1990). Morris (1991; 1994) suggests that attempts to challenge the medical model of disability have tended to neglect the personal experience of disability. However, the study by Oliver et al (1988: 11) sought to show that:

Understanding the consequences of SCI involves a complex relationship between the impaired individual, the social context within which the impairment occurs and the meanings available to individuals to enable them to make sense of what is happening. This is what we mean by social adjustment: it is more than simply the functional limitations that an individual has or the social restrictions encountered; it is a complex relationship between impairment, social restrictions and meanings. This is the interrelationship between the individual and the environment in which they live.

Butler and Bowlby (1997) express concern that acknowledging the pain and inconvenience that individual impairment can cause, may allow some people to renew their claims that the problems that disabled people face are not caused by society, but by their individual bodies. Smith (1999) argues that the emphasis on permanent physical impairments, which limit mobility and ability to negotiate the built environment, has meant that the experiences of people with chronic illnesses have tended to be excluded and received insufficient attention.

## **2.3 Disability studies in human geography**

Geographers have only recently started to examine disability issues. The literature on disability within geography has tended to concentrate on people with physical or sensory impairments. Although 'disability' can be mental as well as physical it is beyond the scope of this study to go into detail about the expanding geographic research on people with mental illnesses. This section reflects on the developments of disability studies in human geography by reviewing some of the various ways that the experience of disability has been interpreted or understood by focusing on people with physical disabilities.

### **2.3.1 The Geography of Health and Healthcare**

The medical geography literature has traditionally been concerned with either studies of disease ecology as an extension of epidemiology, or health care provision and delivery by looking at the location, accessibility and utilisation of health care facilities and services (Dyck, 1999; Gesler, 1991; Kearns, 1995; Park et al, 1998; Verhasselt, 1993). Health care has been dominated by technical solutions and, until recently, medical geographers have used positivistic, quantitative research methods to study populations (Johnston et al, 1994).

Over recent years questioning of the direction, purpose, and content of medical geography has followed calls to take space and place seriously in investigating the complex relationships between people, their health, the places they live in, and places of healing or healthcare (Dyck, 1999; Kearns, 1993). Attempts to elucidate these relationships have been accompanied by a broadening of medical geography's agenda and a reorientation of its concerns. This reorientation has included an increasing use of qualitative research methods and attention to the role of social theory in knowledge construction to produce place-sensitive and subject-centred analyses of the geographical dimensions of health and health

care (Dyck, 1999). Park et al (1998) and Kearns (1995) suggest that the establishment of the journal entitled 'Health and Place' in 1995 was significant as it avoids the word medical in its title. This is symptomatic of a shift in emphasis away from positivist studies towards a more holistic understanding and approach to the geography of health and health care.

More qualitative research methods are now being used by some medical geographers to investigate the more complex social factors that affect people's experience of health, illness and health care providing new interpretations of health care landscapes (Gesler, 1991; Johnston et al, 1994). For example, Eyles and Woods (1983) have attempted to set the central problems of medical geography in a broad social context as well in a spatial one by examining aspects of social policy, poverty, welfare, science and technology. This opens the way to studying specific social groups, such as people with disabilities, in a variety of geographical locations within the geography of health. Other branches of geography such as political and social geography and the social sciences in general, are also caught up in this trend towards using more qualitative research methods (Park et al, 1998).

Curtis and Jones (1998) consider how holistic approaches to understanding people's varying experiences of health and illness may promote consideration of the ways in which mental and physical well-being interact and how this can be associated with sense of place. For example, Gesler (1991; 1992) introduced the idea of 'therapeutic landscapes' into health geography. This blends perspectives from cultural and medical geography to explore the "environmental, individual and societal factors that come together in the healing process in both traditional and non-traditional landscapes" (Gesler, 1992: 735). Gesler (1992) identifies a hospital ward as one example of a landscape in which healing can take place. Gesler's research (1993; 1996) has focused on places with established reputations for healing such as Epidauros and Lourdes. This work challenges dominant understandings of health care sites and furthers the

examination of culturally specific understandings of "healing" and consumer views of health care. Gesler's work has prompted others to look at how health care "landscapes" and other places of healing are perceived and used by local and "pilgrimage" populations. For example, Kearns and Barnett (1999) have focused on a singular tertiary health care facility namely the Starship Children's Hospital in Auckland and how it has been marketed as a 'therapeutic place'. The ideas of a therapeutic landscape will be developed further in Chapter Four with reference to the Burwood SIU.

Within the subdiscipline of health geography, disability has started to be addressed in innovative ways by incorporating and developing neglected ideas about space. For example, Dorn and Laws (1994) build on Kearns' (1993) invitation of 'putting health and health care into place' by insisting that concerns for place must be mediated by concerns for the body, the identities attached to it, and the ensuing "politics of difference" (Young, 1990). A reformed medical geography and an informed health geography according to Dorn and Laws (1994) should therefore problematise the politics of space and the body by introducing the concepts of a *body politics of mobility* and a *body politics of access*. They suggest a *body politics of mobility* calls for the creation of more accommodating public spaces and more accessible public transport systems. This may involve people's ability to network electronically across the world via cyberspace without having to physically leave home. A *body politics of access* could include the ability to network across hearing, vision, mobility, and other sensory impairments with the expansion of modern assistive technologies (Dorn & Laws, 1994; Smith, 1999). Dorn and Laws (1994: 108) conclude that:

The politics of bodily mobility and accessibility disarticulate simplistic views of how to better the everyday experiences of the people living inside bodies that do not conform to social norms.



Kearns (1995) has examined the ways in which intellectual space is being made for difference and also the introduction of gender concerns into the geography of health. He also identifies "concerns with body politics as one way in which the field is being challenged to rethink the subject of its inquiry" (Kearns, 1995: 252).

### 2.3.2 Positivistic Geographies of Disability

Positivist disability researchers assume that "disability is a deficit, a problem in the individual who must be rehabilitated" and they believe that "research must be objective or value free" (Wight Felske, 1994: 182). From a positivistic perspective, Golledge (1993) initiated debate on the issue of having both a geography *of*, and *for*, disability. Golledge (1993) sees disabled people as one of a number of 'special populations' including the poor, the homeless and the ill that endure collective 'disadvantage'. According to Golledge (1993) geographers have paid little attention to disabled people in comparison with other "disadvantaged" groups. He has attempted to make disability a central concern of social geography by suggesting that understanding the worlds of disabled people could offer significant benefits to the discipline of geography and other social sciences as well as to disabled people themselves (Golledge, 1996). Golledge (1996) asserts that geographic studies of disability are beneficial because of the importance of location and proximity to health care facilities and support services, and the difficulties involved in moving through 'disabling space' when mobility is limited, are all significant issues for disabled people. He argues that the physical environment is structured in ways that exacerbate the distorting effect of disability, through careless design and signage.

The article by Golledge (1993: 78) specifies that constructing a geography *of* the disabled requires "defining the worlds in which the disabled live and determining how standard geographic concepts occur in those settings". Golledge (1993) also advocates constructing a

geography *for* the disabled by mapping the places that disabled people inhabit so geographers can devise environmental modifications to improve the immediate problems of accessibility and to enhance the ability of impaired people to cope with the experience of disability. The problems attributable to social and political processes were not issues that Golledge (1993) thought should be addressed by geographers but were long-term goals that were best left to other disciplines. Golledge's work has been criticised because it is oriented towards the medical model of disability, as he tends to conceptualise disability as a personal problem rather than a social or political problem (Gant & Walford, 1998).

### **2.3.3 Interpretative Geographies of Disability**

The debate about objective, positivist worldviews verses qualitative, interpretative and critical paradigms is extensive and ongoing (Ballard, 1994; Wight Felske, 1994). A number of authors have tried to situate their understanding of disability and access issues in the wider context of social and political relations. More geographers are beginning to examine the disabling nature of the built environment and also the way in which public policy perpetuates discrimination. There is also an emerging geographical association between the "disabled body" and restricted movement based around the built environment (Smith, 1999). Curtis and Jones (1998) suggest that geographical studies of disability demonstrate how place can interact in complex ways with social processes and how the impact of place can vary, depending on individual attributes. Geographical research on disability illustrates how social and political structures marginalise people with physical disabilities and generate built forms which further exacerbate the disablement and social exclusion associated with impairment.

Both Gleeson (1996) and Imrie (1996a) have acknowledged the importance of Golledge's (1993) paper in drawing attention to importance of disability as a social issue for geography. However,

both authors were concerned that Golledge's (1993) interpretation of disability was in danger of introducing and perpetuating an individualistic, professionalistic and tragic idea of disability. This deduction led them to call for disability research that is strongly context bound with the aim of developing a geographic perspective which draws upon the social model of disability (Smith, 1999). Gleeson (1996) is critical of Golledge's positivistic perception of disability and on the potential contribution that geographers have to make in transforming the lives of disabled people. On the other hand, Imrie (1996a) criticises Golledge's tendency to view disability as a homogeneous category arguing this simply reinforces negative stereotypes about people with disabilities and the superiority of able-bodied people. If the notion of abnormality is not placed in disabled people but in the context of society which fails to meet their needs, as Oliver (1990) and Abberley (1993) have noted, then a different type of normality is generated. Imrie (1996a) comments that Golledge does not acknowledge how people with disabilities are socialised into particular ways of 'accepting' their inferiority and behaving in ways that appear to conform to society's expectations.

According to Imrie (1996b) the spatial structure of the built environment reproduces dominant power relations and contributes to the oppression and exclusion of people with disabilities. Imrie (1996b) sees that spatial exclusion is built into specific places. For example, he suggests that the marginalisation of disabled people from the workplace often has little to do with their impairments but is more likely to be related to an inaccessible built environment. Imrie (1996b) also acknowledges that public policy is an important context for the perpetuation of disablist attitudes and practices. Imrie (1996a: 398) therefore argues that "a geography of people with disabilities must contextualise their lived experiences as a product of the unequal power relations of ableist socio-spatial structures."

From a materialist perspective Gleeson (1996) argues that disability is a form of oppression produced by socio-spatial structures in society, rather than biological and functional impairment. Gleeson (1996) believes that disabled people experience social and material deprivation in specific ways that distinguishes them from other oppressed groups. The materialist position proposed by Gleeson (1996) is that disability must be opposed at a deeper socio-political level by understanding the social processes which create disabling environments. Instead of having a geography *of* and *for* disabled people as Golledge (1993) suggested, Gleeson (1996: 395) sees that the challenge is "to pursue a geography *with* disabled people which seeks the goals of material justice and political emancipation that are shared by many contemporary social movements". Gleeson (1996: 365) believes that geographers need to seek "a political engagement with disability within the struggles of disabled people themselves". He is therefore stressing the validity of knowledge and suggests that geographers must speak *with* rather than *for* the oppressed "other".

Sibley (1995: ix) suggests that the "human landscape can be read as a landscape of exclusion". Theories on exclusion have resonance to people with disabilities and their exclusion from public spaces. Like Young (1990), Sibley (1995: xiv) recognises that exclusion can be based on gender, race, age, sexuality, and mental and physical disability and that "exclusions take place routinely, without most people noticing". Mainstream society represents itself as normal and feels threatened by the presence of others who are perceived to be different and "other". According to Sibley (1995) difference is harnessed in the exercise of power and subordination of minorities with the relegation of weaker groups in society to less desirable environments. The variation in response to difference is due to some localities and some people being more tolerant to difference in social and spatial terms (see, for example, Dear et al, 1997). In the book *Mapping the Subject*, Pile and Thrift (1995) suggest that the body can take on different qualities at different times depending on the way the body

is coded in a social setting. It looks at hostile encounters and perceptions about different places where people stand out and feel out of place.

Dear et al (1997) illustrate that responses to people with disabilities vary according to hierarchical rankings of the acceptability of different disabilities, from the least to most preferred types of disability. Westbrook et al (1993: 617) state that:

Negative social attitudes towards people with disabilities are most likely to be expressed in terms of exclusion from, or lack of access to, social roles, activities and facilities. Thus people with disabilities are less likely to be educated, to work, to marry or to be able to go to public places.

Attitudinal variations to various disabilities exhibit spatial and temporal dimensions and when different facilities designed to assist people with disabilities are considered, actual behaviour may differ from expressed attitudinal preferences (Dear et al, 1997). The acceptance of various disabilities has changed over time and often depends on the context in which they are encountered. Generally, physical disabilities have demanded greater tolerance than intellectual disabilities (Tennant, 1996). Common and less visible disabilities (such as, diabetes and asthma) are even more widely accepted. Conversely, visible disabilities (for example, cerebral palsy), disabilities involving mental illnesses or disabilities for which people are seen as morally responsible for are the most stigmatised. Westbrook et al (1993) suggest that attitudes towards people with disabilities are becoming less negative and this appears to be a generalised effect rather than changing the relative acceptability of particular disabilities. The more intimate the setting in which a disability is encountered, the less willing people are to accept it because of their anxieties. Dear et al (1997: 472) go on to argue that:

Space does not merely reflect the social constructions of disability; instead, space itself is integral to the production and perpetuation of disability.

By examining feminist literature relating to the links between biology, the body and the social status of women, Butler and Bowlby (1997) discuss the ways in which concepts of and attitudes towards disability affect disabled people's ability to move freely within public spaces. They suggest that only those people whose appearance and behaviour 'conforms' to what society considers 'appropriate' and 'normal' can maintain a physical presence in public space without social challenge and negative reactions. Although Butler and Bowlby (1997) focus on the experiences of people with vision impairments in public space in Reading, England, they also discuss the relevance of their research more generally, for people with other disabilities.

Some disability research by non-geographers such as Hahn (1986; 1989; 1997) and Oliver (1990; 1992; 1996) reveals geographic aspects of disability and oppression. For example, Hahn, a political scientist, has discussed the challenges of creating a more inclusive urban built environment and the role of ableist "body images" in marginalising disabled people. Chouinard (1997) has defined *ableism* as any social relations, practices, institutions, and ideas that presume all people are able-bodied. Ableist geographies therefore refer to the environments which incorporate and perpetuate the physical and social barriers to the participation of disabled persons in everyday life (Chouinard, 1997). Hahn (1986) considers the importance of distance for disabled people in Los Angeles and illustrates their difficulties in moving through space because of the city's high level of urban sprawl and lack of accessible public transport. He has also looked at issues of social justice and argued that:

People should not be prevented by artificial barriers from participating in community life, and mastery of the existing environment must not be an essential prerequisite for exercising the rights of citizenship (Hahn, 1986: 273).

Clearly, research on disability has increasingly been guided by a definition that focuses on the interaction between the individual and the environment. Both Hahn (1988) and Oliver (1990)

consider it more appropriate to situate the forms of oppression facing people with disabilities in the context of what they call the "minority group model". This perspective does not regard disability as a personal deficiency. Instead it suggests that discriminatory attitudes are the primary source of problems for disabled people and that the environment is shaped by public policies, which reflect prevalent social attitudes and values.

### **2.3.4 Emancipatory Approaches to Studying Disability**

Issues of human rights, citizenship and the empowerment of people with disabilities are receiving greater attention (see, for example, Davis, 1999; Brown, 1994, Wight Felske, 1994; Birkenbach, 1999). Emancipatory approaches to studying disability have emerged in response to the perceived failure of the positivist and interpretative research paradigms in adequately encapsulating the essence of disabled people as citizens (Park et al, 1998). Emancipatory research places disabled people's voices at the centre of the research process (Roulstone, 1998a) and aims to empower disabled people in the process (Ramcharan & Grant, 1994). Suggestions for more emancipatory approaches bring personal and political challenges for the researcher. There is an increasing sensitivity to the politics of research which has heightened concern with how, as well as what, knowledge is constructed about the "other" (Dyck, 1999; Dyck & Kearns, 1995; Chouinard, 1997; Park et al, 1998).

Feminist and disability research has problematised the power relationship between the researcher and the researched in "the field" (Dyck & Kearns, 1995). According to Oliver (1992; 1996), the process of research production has been alienating for many disabled people and also for researchers. The researcher is seen as the expert who has total control of the research process. Therefore, the research experience is often an isolating one reinforcing the dominant idea of disability as an individual problem. Oliver (1996) argues that research

on disability has consistently failed to involve disabled people, except as passive objects for interviews, which may of benefit to researchers but does nothing to serve the interests of disabled people. Both Imrie (1996a) and Oliver (1992) suggest that the social relations of research production are problematic because they tend to reflect the dominance of an elitist structure which regards the researched as somehow subordinate to the researcher. England (1994: 80) proposes that:

Feminist and poststructural challenges to objective social science demand greater reflection by the researcher with the aim of producing more inclusive methods sensitive to the power relations in fieldwork.

She highlights some of the ethical dilemmas that face researchers conducting fieldwork, especially with regard to the hierarchical relationship between the researcher and those being researched. Exposing the social construction of knowledge is central to feminist praxis. According to Staeheli and Lawson (1994: 97) this involves:

critically examining the relationships between the researcher and the researched, questions asked and not asked, interpretations of data, and highlighting the roles of women and feminists as political agents... in our position as academics, a key element of our praxis is linking experiences of oppression, domination, and resistance through the research process.

The position of the researcher plays a vital role in the research process, in the field as well as in the final text (see, for example, Dyck & Kearns, 1995; England, 1994). The next chapter will discuss the social relations of research production and ethical issues involved in speaking "for" other people in more detail.

A number of authors (see, for example, Imrie, 1996a, Oliver, 1992; 1996; Ramcharan & Grant, 1994; Roulstone, 1998a; Ward & Flynn, 1994; Zarb, 1992) have called for an emancipatory and participatory research paradigm in which disabled people need to be involved in all stages of the research process. This would help to make disability research more relevant to the lives of disabled people and more influential in improving their material circumstances and quality of life. Ward and Flynn (1994) suggest that if research is to



contribute to the empowerment of people with disabilities it must do several things. Firstly, researchers have to share their knowledge and findings with other disabled people to raise consciousness and to broaden the base of the Disability Movement and secondly research must influence policy makers to make policy changes that will work towards the empowerment of people with disabilities. Barnes (1992) argues that qualitative research is fundamental to the emancipatory research paradigm. In addition to examining legal systems and the practices of social control agencies, Sibley (1995) asserts that explanations of exclusion on the barriers and constraints on activities are needed from the perspective of those who are excluded. Chouinard believes that politically informed research is necessary to challenge the "ableism" of geography (Chouinard & Grant, 1995; Chouinard, 1997).

Chouinard and Grant (1995: 138) illustrate that ableism and heterosexism are "significant sources and structures of oppression." Chouinard challenges geographers to recognise the ways in which geography as a discipline has traditionally been, and is, 'ableist' in its practices and subject matter (Chouinard and Grant, 1995). The presumption of ableism in geographic literature helps to render people with disabilities as marginalised, oppressed and largely invisible 'others'. For example, Chouinard (1995) argues that if a person with a physical disability encounters an environment that is not designed to accommodate their wheelchair, the environment actively marks that person as different and out of place. This reinforces the belief that able-bodied people are qualitatively distinct from those who are disabled. Conversely, when the environment is designed to accommodate both wheelchair users and walkers the physical signal for differentiation is absent which facilitates a more positive encounter.

Matthews and Vujakovic (1995) recognise that the views of physically disabled people are rarely acknowledged in mapping and urban design. They have generated maps of the city centre in Coventry, England, by employing the direct knowledge of wheelchair users in

co-operation with university students, to illustrate and highlight accessibility issues. There were many inaccessible parts of the city where movement over space was restricted by physical obstacles such as uneven surfaces, steep inclines and stairs. Matthews and Vujakovic's (1995) mapping project found that urban environments are landscapes of exclusion for many wheelchair users because the way space is organised contributes to their sense of being 'other'. They suggest that geographers and cartographers could help to heighten awareness and the break down the barriers inherent in the built environment, which disadvantage disabled people. Matthews and Vujakovic (1995: 1082) conclude that:

people with physical disabilities are sensitive to the characteristics of geographic space. Environments can both enable and disable. For wheelchair users to be integrated fully into society there is a need not only to provide good information on potential problems but also to allow active participation in all stages of urban design.

Smith (1999: 49) argues that "a geographical perspective on disability should be more than just another discipline offering its "expertise" to develop a deeper understanding of a pre-existing definition of disability". For many people the logical connection between physical disability and the physical environment (for example inaccessible buildings and public transport systems) provides a justification for geography to study how disabled people move around. According to Smith (1999) future understanding about disability needs to rethink the ideas of spatiality such as "access" and "mobility" because "disability", like other identities, has to be considered in light of the context in which identities are developed (see also, Zola, 1993). Lately geographers working on identity have been using spatial metaphors (see, for example, Bondi, 1993b; Smith & Katz, 1993) to highlight the experience of the physical and the social world within any analysis of oppression (Nast & Pile, 1998; Smith, 1999). For example, Smith and Katz (1993: 68) argue for a return to "the spatial" in any analysis of identity politics and they suggest that:

... spatial metaphors have become a predominant means by which social life is understood. "Theoretical spaces" have been "explored", "mapped", "charted", "contested", "colonised", "decolonised", and everyone seems to be "travelling".

However, Dorn (1998) disputes the use of the spatial metaphor *nomadism* when considering the life experiences of Patty Hayes a disabled activist, by arguing that such a metaphor is disableist. He describes Patty's story of coping with environmental and perceptual barriers, and mastering the everyday challenges involved in learning to manoeuvre her wheelchair to illustrate the development of *geographic maturity*. Rather than the metaphor 'nomadism' Dorn (1998) prefers the metaphor *spatial dissident* to consider the spatial experiences of people who reject normative body space. Dorn (1998) shows how a 'spatial dissident' demonstrates a mature form of environmental sensitivity by responsive to changing environmental conditions by helping to create and expose new routes for others to follow. Smith (1999) recognises the potential power of spatial metaphors in rethinking the politics of disabled identities provided they are thought through and applied carefully. As Smith and Katz (1993) note the appeal of spatial metaphors is their ability to decentre and destabilise previously fixed realities and assumptions.

Morris (1993) describes how disability research has tended to treat gender as invisible, or separates the issue of gender, to focus on disabled women's experiences (see, for example, Lonsdale, 1990; Morris, 1989). She argues that Oliver et al's (1988) study *Walking into Darkness: the experience of spinal injury* was inadequate because it assumes that the experiences of men with SCI are representative of the experiences of all people with SCI. She identifies that work and family relationships are two areas of life which are characterised by social meanings of masculinity, yet there was no consideration of how gender as a social construct gives particular meaning to these areas of experience for the men in the study. However, Oliver et al (1988) did recognise that research on the experiences of disabled women is needed.

According to Morris (1992; 1994), disability issues are also generally invisible in terms of the mainstream feminist agenda. She suggests that disability research can learn a great deal from feminist research methodology especially the principle of making the personal political. Morris (1992; 1994) also recognises that research needs 'give voice' to disabled people's personal experiences and it must aim to empower disabled people. Chouinard and Grant (1995) have questioned why the growth of radical and feminist geographies has largely excluded disabled and lesbian women as both subjects and producers of research. They suggest that truly 'empowering' geographies would endeavour to include all types of women as subjects of geographic research. McDowell (1991) acknowledges that there has been a conscious attempt to recognise diversity and differences among women, (particularly women of different class positions, ethnicities, religions, sexual orientations, and nationalities) which she argues, will strengthen feminist scholarship.

Cormode (1997) acknowledges that the number of disabled academics is slowly increasing. She suggests that improved educational provision for disabled children, technological advancements, government legislation for equal opportunities and physical accessibility have enabled more people with disabilities to enter and remain in academia. Nevertheless, Golledge's (1997) account of his academic rehabilitation after the onset of sudden vision impairment illustrates that substantial physical and social barriers still remain. While Chouinard (1995, 1997) describes her experiences of being an academic, disabled woman with rheumatoid arthritis by detailing the difficulties she has encountered in trying to continue working and obtain appropriate accommodation for her disabilities. The university that Chouinard works at has been a significant site of her oppression, which has taken many forms, for example, the lack of physical access to her office and the use of ableist standards to evaluate her academic contributions. According to Chouinard (1997), geographic research which challenges ableism, needs to examine the practices which exclude people with

disabling differences from the various spaces of academic life and contributes to their absence as students and lecturers.

## **2.4 Chapter Summary**

This chapter has shown that definitions of disability depend on the way in which society as a whole perceives specific disabilities and that what is defined as 'disabling' is subject to change. Geographers have only recently started to research and write about the experiences of people with disabilities. Absolute consensus as to the definition of disability is still yet been reached (Ratima et al, 1995). The medical model of disability, which focuses on individual impairments, has traditionally guided disability research. However, more geographers are beginning to use the social model of disability to examine how the spatial structure of the built environment contributes to the oppression and exclusion of people with disabilities and also the way in which public policy perpetuates ableist attitudes and values. Social theories of the body are becoming increasingly important in contemporary understanding of disability. Emancipatory approaches to disability have also emerged which venture beyond characterising disability as a physical or social problem to focus on the social relations of research production and making disability research more relevant to people with disabilities.

The following chapter will concentrate on the research methods used in this study. It will also set the scene by illustrating some of the injury related and demographic characteristics of the people with spinal cord injuries that were interviewed as part of the study.

## **CHAPTER THREE:            Methodology**

### **3.1 Introduction**

The previous chapter alluded to some of the research methods which have been used in recent geographic research on disability. This chapter will describe the various data sources and research methods that have been used in this study. The selection of research methods in this study is justified and any problems or limitations are identified. A description of the data collection process and the questionnaire are also provided. At the end of this chapter some of the demographic and injury related characteristics of the participants in this study will be described.

### **3.2 Secondary Data Sources**

Secondary data refers to information that has already been collected such as academic research, census data, statistics on employment and unemployment, hospital records, company reports and planning documents. One important role of secondary data is to provide a context in which primary data will subsequently be collected and analysed (Lindsay, 1997). In the current study, the use of secondary data helped provide information on spinal cord injuries and on contextual information about the New Zealand labour market, vocational rehabilitation and accident compensation. The Internet has been a valuable source of information for finding recent secondary data. The inflexibility of some secondary data can limit its' usefulness. For example, the ACC *Injury Statistics* (1997a) does not classify spinal cord injuries separately, and the *Disability Counts* survey conducted by Statistics New Zealand (1998) does not define specific types of disability. Attempts were made to gain access to the ACC database of people with SCI to get a random sample of the spinally injured population. However, due to the Privacy Act (1993) this was not feasible.

An extensive literature review was a vital part of this research. This helped to provide important historical and contextual information and enabled the researcher to identify relevant research that has been done in geography, disability studies and rehabilitation fields. It also made the researcher aware of some of the issues involved in researching disability (see, for example, Moore et al, 1998) and provided an overview of the range of research methodologies in human geography and the social sciences (see, for example, Eyles & Smith, 1988; de Vaus, 1995; Flowerdew & Martin, 1997; Lindsay, 1997; Robinson, 1998).

The most widely used methodology to study the employment outcomes of people with SCI has been to follow patients after discharge from one particular hospital or rehabilitation facility (see, for example, Alfred et al, 1987; Burnham et al, 1996; Castle, 1994; De Vivo et al, 1987; Tarrico et al, 1992; van Asbeck et al, 1994). Previous studies on employment after SCI have shown varying employment outcomes due to differences in the characteristics of the participants, both in terms of demographic and injury-related variables (Krause & Anson, 1996). Young et al (1994) suggest that many previous studies have been limited by focusing on people who have been recently injured or who are not very far removed from their rehabilitation. Notable exceptions are De Vivo et al (1987), who followed people with SCI for seven years after sustaining their injuries. The group studied by Young et al (1994) had a mean time since injury of eleven years and Krause's (1992) study sample had a mean of 18.6 years post-injury. Various methods of follow up have been used in previous studies including face-to-face interviews, surveys by mail and telephone, and medical review. Krause and Anson (1996) also suggest that many studies have used current employment status as the only outcome measure which tends to underestimate the number of people with SCI who return to work, as many people who do enter into employment may not continue to work.

### 3.3 Primary Data

Primary data refers to data that is collected directly by the researcher(s) for a particular purpose. Lindsay (1997: 22) suggests that although the process of primary data collection "is often time-consuming and laborious, it has the advantage of giving the researcher as much control as possible over the data used". In this study the primary data collection consisted of interviews with seventy spinal cord injured people, with representatives from various organisations and community support services who are involved in the rehabilitative care and employment of people with SCI (Appendix C).

There are ethical issues involved in speaking "for" marginalised groups of people (see, for example, Dyck & Kearns, 1995; England, 1994; Kinson, 1995; Plowman, 1995; Valentine, 1997). England (1994) argues that the position of the researcher plays a critical role in the research process, in the field as well as in the final text. She also suggests that:

A researcher is positioned by her/his gender, age, "race"/ethnicity, sexual identity, and so on, as well as by her/his biography, all of which may inhibit or enable certain research method insights in the field (England, 1994: 85).

Most feminist geographers are committed to situating knowledge and recognising that interpretations are context-bound and partial, rather than detached and universal (Johnston et al, 1994). As a female, middle class, pakeha, able-bodied person I have tried to give an accurate analysis of the employment experiences of people with spinal cord injuries. Using face-to-face in-depth interviews with people who have sustained SCI, have given these people the opportunity to express their personal feelings and experiences.

The current study was designed to examine the employment status of persons with SCI, avoiding several limitations of previous studies. So as to gain a clearer understanding of the extent of employment following spinal cord injuries this study distinguishes among full-time and part-time workers, full-time and part-time students, people who are unemployed and



looking for work, and those who are unemployed and not seeking work. This study also measures employment status at several different points in time to avoid underestimating how many people do work at some stage after SCI.

### **3.3.1 Selection of participants**

The focus of this study was on people with traumatic SCI because of its sudden onset. Therefore, to be included in this study, at the time of interview individuals had to have sustained a traumatic SCI at least six months previously and be over eighteen years of age. The majority of the participants in this study were accessed from the Burwood Hospital SIU and were returning for reassessment or further medical treatment. Generally, people with SCI who live in the top half of the North Island are admitted to the Otara SIU for rehabilitative treatment, and the Burwood SIU receives patients from the rest of New Zealand (Tertiary Services Committee, 1995). Consequently, people with spinal cord injuries from a variety of locations around New Zealand were interviewed (Figure 3.1). This enabled the scope of this research to be broadened to look at the employment issues for people with SCI in New Zealand and not just in Christchurch. The sample represents a cross-section of people with SCI, including people been recently injured and those who had lived with their injury for a substantial number of years (up to forty two years).

Six additional participants were gained through the sampling strategy known as snowballing. The people who were interviewed sometimes suggested other possible participants to be part of the study. Robinson (1998: 385) suggests that the snowballing method “may be used if the research focus is upon a relatively small group possessing certain characteristics. A common example is in investigations of people with particular disabilities”. Two New Zealand studies, Sherrard (1996) and Newcombe (1991) which have studied people with spinal cord injuries, have both used the snowballing sampling strategy. Snowballing was considered an

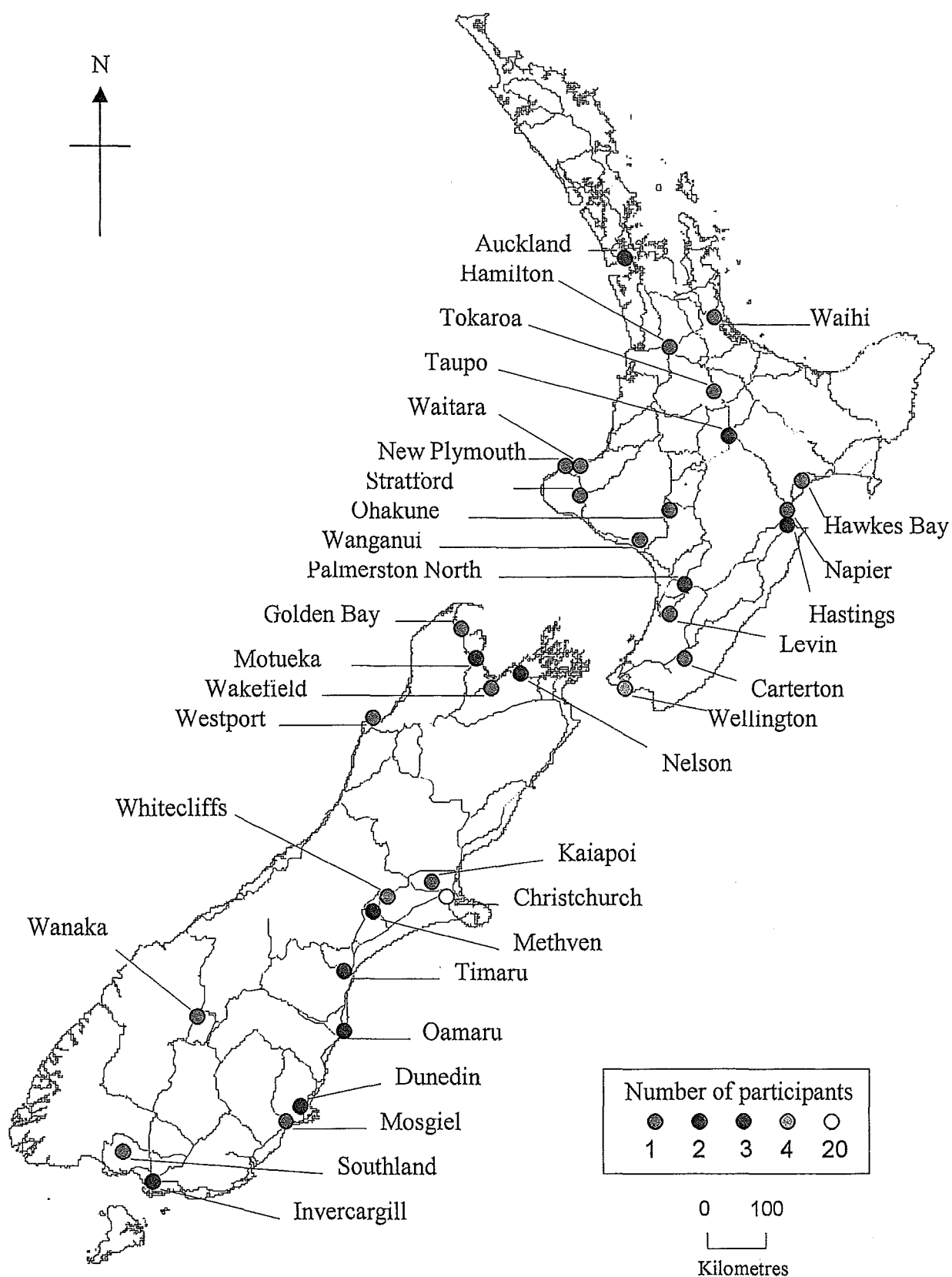
appropriate means of obtaining additional participants for the present study because of established informal networks. However, it is acknowledged that the snowballing sampling method is not random. When people did suggest other possible participants for this study the people they suggested were all working (one full-time and five part-time). Therefore, the results for this study need to be considered as possibly having higher levels of employment than for the general SCI population.

This study obtained ethical approval from the University of Canterbury's Human Ethics Committee. Permission was also obtained from Professor Alan Clarke, the Clinical Director of the Burwood Hospital SIU and Mr Bill McDonald, the General Manager of Burwood Hospital to access patients from the Burwood Hospital SIU who were returning for reassessment or further medical treatment.

### **3.3.2 The Setting**

The setting for the present study was particularly important because most of the participants used wheelchairs for mobility. Sixty four of the seventy interviews were conducted with participants who were at the Burwood Hospital SIU for reassessment or further medical treatment. The research context at the Burwood SIU meant that people from a variety of locations around New Zealand could be interviewed (Figure 3.1). The participants were asked where they would like to be interviewed. The interviews took place in a variety of places in and around the Burwood SIU. Half of the seventy interviews took place in the hostel common room. The rest were conducted outside when the weather was nice, in the dining room, in individuals' rooms in the hostel, in the ward when people were on bed rest, or in the gym, self care units or the family room. The locations for six other interviews had to minimise any transport difficulties for the participants to facilitate a higher response rate.

Figure 3.1 Map showing where the participants were living at the time of interview



Therefore, three interviews were carried out in the participants' homes and three interviews were also conducted at participants' workplaces, at times that were suitable for them and the researcher.

### **3.3.4 Data Collection**

Because no published New Zealand research has specifically looked at employment issues for people with SCI it was decided that both quantitative and qualitative research methods would be used to establish a baseline for further research. Quantitative data has been used to provide the hard evidence required for policy and service planning, as anecdotal accounts rarely win arguments or resources (Katzehellenbogen, 1998). Quantitative data is important for describing the numbers and characteristics of people with SCI, in assessing barriers to accessing services and employment, levels of service awareness and use. In contrast to quantitative methods, qualitative methods provide flexibility and varied strategies necessary for exploring different dimensions of a phenomenon (Dyck, 1999; Robinson, 1998). For example, Curtis and Jones (1998: 657) recognise that:

Qualitative studies have the potential to explore in depth the possible causes of the findings of statistical analysis, which are often essentially descriptions of the statistical associations between a limited set of measurable indicators.

Qualitative methods are therefore, able to explore the importance of local context as well as reveal issues and meanings undiscovered in quantitative methods. Curtis and Jones (1998) emphasize that qualitative methods recognise the need to be reflective which raises questions about how 'objective' and neutral it is possible to be in the research process. Dyck (1999) acknowledges that qualitative methods have also been influential in decentering the authority and dominance of biomedical knowledge by introducing subject-centred perspectives to medicalised events and health care provision.

A questionnaire was designed specifically for this study to provide consistency and focus to each interview (Appendix D). Advice from those with SCI was elicited in the design of the questionnaire. It was also pre-tested to ensure that the questions were appropriate and easy to understand. The questionnaire focused on different periods of time: prior to the injury, at the time of the injury, since the injury and at the time of the interview. It included closed questions that required structured responses as well as open-ended questions which gave the participants control over what they told the researcher, and also allowed them to speak for themselves.

The face-to-face nature of the interviews meant that the researcher was able to use probing techniques to ascertain people's attitudes and feelings in an effort to facilitate conversation and enhance the qualitative data. A general understanding of SCI and an awareness of the practical implications of SCI were essential for the researcher to be able to empathise with the individuals. Flexibility was involved in each interview. This was to encourage and allow the participants to discuss their lives and the diverse range of factors that influenced their employment status. As some tetraplegics with limited hand function would have been unable to fill in the questionnaire, the researcher administered the questionnaire and recorded the responses with all the participants. Note taking was used rather than tape recording as it was felt that people might have been less forthcoming with information if the interviews had been taped. This also saved valuable time by not having to transcribe the interviews.

The nature of this study was explained to potential participants and they were given an information sheet to provide details of the study and to establish the legitimacy of the study (Appendix E). The individuals were told that the research was being conducted independently and was not associated with any organisation (such as ACC). They were also assured that all information would be treated as confidential and that their names were not

written on the questionnaires. The participants had the opportunity to ask questions and have them answered to their satisfaction. At the conclusion of the interviews informed consent was obtained from the respondents (Appendix F). Three people declined to participate in the study (two males and one female). Their reasons for not wanting to participate included being "too old", "too lazy" and "simply not interested".

A total of seventy interviews were conducted with spinal cord injured people and this formed the major part of the primary data collection for this study. The interviewing for this study took place between the 30<sup>th</sup> March and 25<sup>th</sup> August 1999. The majority of the interviews were carried out between each participant and the researcher, normally with no one else in attendance. On some occasions the participants' partner, carer or other people with SCI were present during part or the entire interview. Parts of the interview were enhanced by the presence of another person, enabling the obtaining of more comprehensive information. The interview process lasted between twenty five minutes and two and a half hours.

At the beginning of each interview participants were asked about the cause and nature of their injury. Considering the purpose of the interview this seemed to be a necessary and appropriate starting point, and without exception all the respondents generously provided details about their injuries. The rest of the interview contained questions on workforce participation before injury, vocational and support services for people with SCI, gaining employment after injury, and on peoples' workplaces or being unemployed. Each interview concluded with some questions to establish background information about the characteristics of the people in the study. The majority of the participants seemed to relish the opportunity to talk about their experiences, voice their opinions and any of their frustrations and/or achievements. During the interviews the individuals also talked about a variety of additional matters such as details about their injuries and any medical problems, activities of daily

living, emotions and body image, travel experiences, the death of people close to them, and details relating to their personal life and relationships.

### **3.3.5 Data Analysis**

This section will briefly describe the techniques that have been used to analyse the data that was obtained from the interviews with spinal cord injured people. Various descriptive statistics were generated on the injury related and demographic characteristics of the participants, and also on the employment variables. Following data collection, the data was computer coded and analysed using the Statistical Analysis System (SAS) software package, to determine which demographic and injury related variables were associated with specific employment status outcomes. The results of this analysis are presented in Chapter Six. A result was considered statistically significant if the *p*-value was 0.05 or lower.

## **3.4 The characteristics of the people in this study**

Spinal cord injuries happen mostly to young people, and mostly to males (usually around 80%). This is because males are generally more likely to take risks or behave impulsively compared to females (Corbet et al, 1998). In this study interviews were conducted with 60 men and 10 women (85.7% versus 14.3% respectively). It was not considered necessary to get an equal male/female gender ratio because of the expected difficulties in recruiting enough females. However, the small number of women has made it difficult to make gender comparisons. The majority of the participants (82.9%) were European followed by Maori (8.6%), Pacific Islanders (7.1%) and one Indian (1.4%).

**Table 3.1 Age when injured**

Age when injured (years)	Male		Female		Total	
	n	%	n	%	n	%
15-24	28	46.7	4	40.0	32	45.7
25-34	17	28.3	2	20.0	19	27.1
35-44	6	10.0	2	20.0	8	11.4
45-54	6	10.0	2	20.0	8	11.4
55+	3	5.0	0	0.0	3	4.3
Total	60	100	10	100	70	100

(Source: Access to employment opportunities for people with SCI Survey)

The participants' age at the time of injury ranged between 15 and 65 years, with 45.7% being injured before 25 years (Table 3.1). The mean age when injured was 29.9 years, with a standard deviation of  $\pm 12.0$  years. At the time of interview the respondents' ages ranged between 18 and 65 years of age. The majority of individuals (32.5%) were in the 25-34 age group (Table 3.2) and the mean was 37.7 years with a standard deviation of  $\pm 12.2$  years. The time since participants' injuries varied between 6 months and 42 years ago. During this time methods of treatment and rehabilitation of SCI will have changed. The mean time since injury was 8 years.

**Table 3.2 Age when interviewed**

Age when injured (years)	Male		Female		Total	
	n	%	n	%	n	%
18-24	8	13.3	1	10.0	9	12.9
25-34	20	33.3	3	30.0	23	32.9
35-44	16	26.7	2	10.0	18	25.7
45-54	9	15.0	4	40.0	13	18.5
55+	7	11.7	0	0.0	7	10.0
Total	60	100	10	100	70	100

(Source: Access to employment opportunities for people with SCI Survey)

In this study level of injury was classified as either tetraplegic or paraplegic. There were slightly more paraplegics (52.9%) than tetraplegics (47.1%) (Table 3.3). Over half of the



participants (54.3%) had incomplete injuries, and 45.7% had complete injuries. There were fifty seven wheelchair users (17 power wheelchair users and 40 manual wheelchair user) and thirteen people were walkers.

**Table 3.3 Participants' level and completeness of injury**

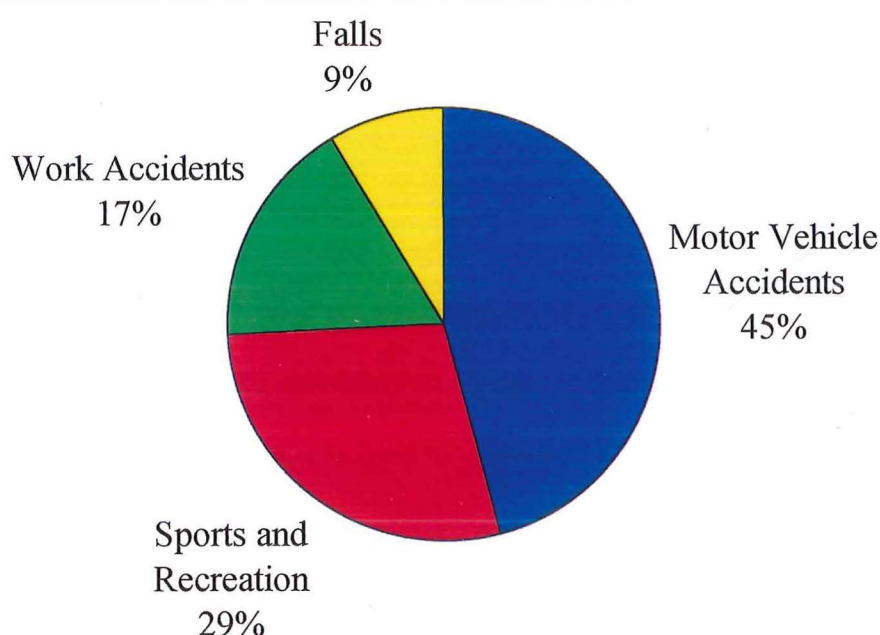
Level and completeness of injury	Frequency (n)	Percent (%)
Complete Tetraplegic	13	18.6
Incomplete Tetraplegic	20	28.6
Complete Paraplegic	19	27.1
Incomplete Paraplegic	18	25.7
Total	70	100

(Source: Access to employment opportunities for people with SCI Survey)

In this study the leading cause of the participants' spinal cord injuries was motor vehicle accidents (45%), next were sports and recreational accidents (29%), followed by work accidents (17%) and falls (9%) (Figure 3.2). The 32 motor vehicle accidents included 21 car accidents, 7 motor cycle accidents, one person was involved in truck accident on his way to work, one person had a tractor accident at home, one pedestrian was hit by a car, and one cyclist was hit by a drunk driver. Car accidents caused eight of the ten females' spinal cord injuries and the other two were recreational accidents. Rugby accounted for six participants' injuries to the spinal cord. Four people were paralysed as a result of diving/swimming pool accidents and two people were dumped by waves at the beach. Another eight individuals were involved in sports and recreational accidents that were the result of mountain biking, paraponting, jet boating, motor cross, horse riding, softball, hunting, and stock car racing accidents. The twelve work accidents included four forestry related accidents, a fall from a machine, a hay baling accident, an army training accident, a construction accident, a truck accident at work, a top dressing accident to a pilot, and four for which the cause was not specified. Six of the participants' spinal cord injuries were due to falls. These involved falling

off a ladder, from a tree, down a ten-meter bank, off a two-story house, down a wall while fishing and one was not disclosed.

**Figure 3.2 Cause of SCI for the participants in this study**



It is not possible to suggest how representative this sample of people with SCI is compared to the spinal cord injured population in New Zealand as a whole, because of the lack of data available on this group of people. The New Zealand Spinal Trust is currently reviewing the medical records at the Otago and Burwood Spinal Units to determine the causes of all SCI in New Zealand. Professor Alan Clarke suggests that in New Zealand the “increase in spinal injuries is not from road accidents and rugby anymore but from recreation” (Wenley, 1997). Research by the New Zealand Spinal Trust (see Armour et al, 1995) prompted the New Zealand Rugby Football Union to implement new scrum safety guidelines and compulsory safety seminars for coaches. Since then spinal cord injuries from rugby and especially scrum impact injuries have fallen dramatically (New Zealand Spinal Trust, 1998).

The causes of spinal cord injuries show spatial and temporal variations at national and regional scales. For example, the most recent statistics for the United States released by the National Spinal Cord Injury Association in August 1995 show that motor vehicle accidents (44%) were the leading cause of SCI, followed by acts of violence (24%), falls (22%), sports (8%) and other (2%). Acts of violence have overtaken falls as the second most common cause of SCI in the United States and in some areas compete for first place (Cure Paralysis Now, 1997).

### **3.5 Chapter Summary**

This chapter has discussed both secondary and primary data sources that have been used in this research. Using secondary data helped to provide the context for the primary data that was subsequently collected. Seventy interviews were conducted with spinally injured people, and this formed the major part of the primary data collection for this study. This chapter has described the methods by which data was collected and then concluded by presenting some of the demographic and injury related characteristics of the people with SCI who were interviewed.

The researcher believes that the seventy people with SCI who were interviewed provided a broad cross section of the people with traumatic SCI in New Zealand, in terms of geographical location, demographic and injury related variables. The results in the following chapters must be considered in light of the research limitations presented in this chapter. The research context at the Burwood SIU provided the best possible access to people with SCI from a variety of locations around New Zealand, given the time constraints placed upon this study and the relatively small size of the spinally injured population. Although the researcher has included people with SCI in all stages of the research process, it has been recognised that

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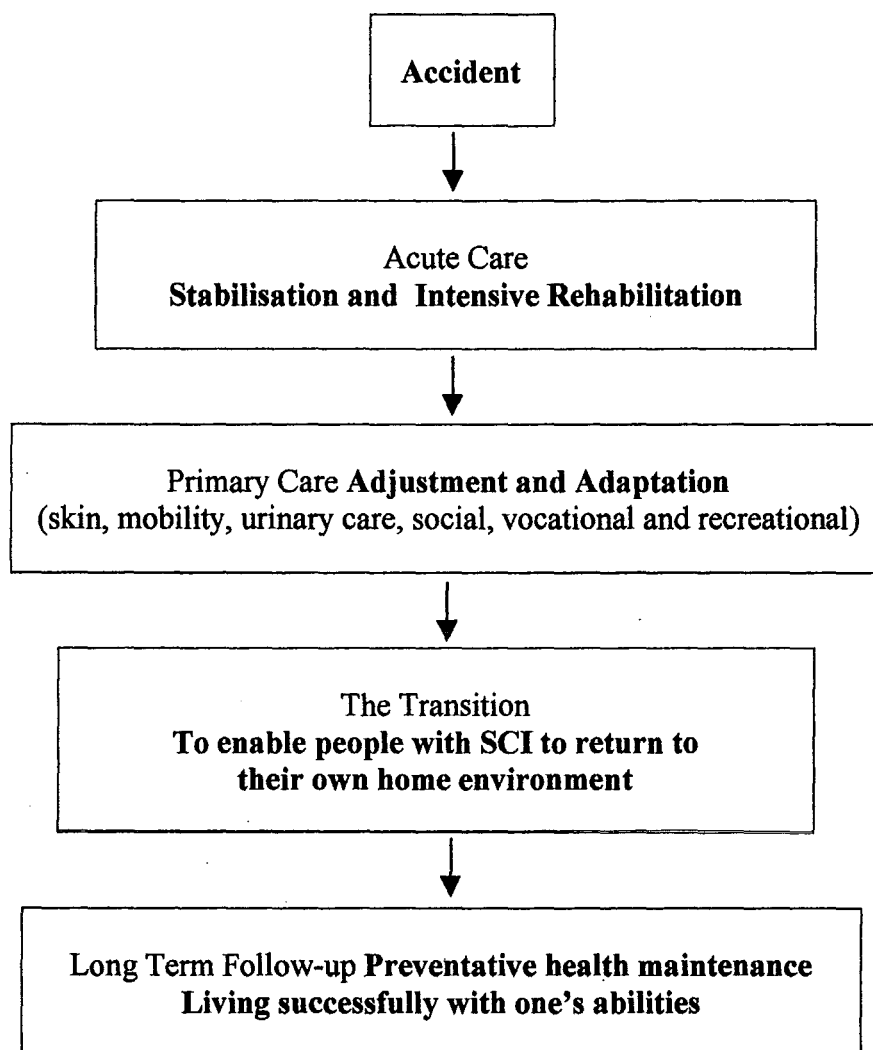
## **CHAPTER FOUR: Vocational Rehabilitation at the Burwood Spinal Injuries Unit**

### **4.1 Introduction**

This chapter concentrates on SCI rehabilitation. It specifically focuses particularly on the provision for, and timeliness of, vocational rehabilitation within the rehabilitation process at the Burwood SIU. On the basis of previous research findings and the interviews conducted for this study it is argued that vocational rehabilitation should be introduced early on in the rehabilitation process. Such moves are likely to help improve positive employment and productivity outcomes for people with SCI.

### **4.2 Spinal Cord Injury Rehabilitation**

The aim of SCI rehabilitation is to help people who sustain SCI attain the maximum level of functioning and independence in the community. Figure 4.1 illustrates the critical medical pathways that are involved in the rehabilitation of people with SCI. People who survive this injury are unlikely to do so without immediate emergency care, followed by acute medical and nursing care. After a patient's acute medical needs have been addressed, activities of daily living (ADL) and mobility skills need to be learnt to prevent medical complications and to enable a patient to be discharged with the necessary skills to their home environment. Reassessments at defined intervals (for example, six months, one year and two years after injury) are the primary means to monitor progress and identify any secondary complications after discharge. Even the best medical care is incomplete without social support and encouragement from family and friends (Jackson Memorial Medical Center, 1998a; Parker, 1996; Lindemann, 1981).

**Figure 4.1 Critical Pathways in Spinal Cord Injury Services**

The British Spinal Injury Association (SIA) commissioned a study to investigate the outcome of specialist versus non-specialist care of SCI and to produce empirical evidence to show how people with SCI actually live. At the time of the study (1997) the SIA had 5642 members with SCI and a questionnaire was included with their winter newsletter. There were 823 responses received 23 of which were excluded for not satisfying the inclusion criteria for the study. Of the respondents ninety (13.6%) had not utilised a SIU system at the acute stage and 702 (86.4%) had been to a specialised SIU following injury. The study provides conclusive, statistically significant, evidence that those who have access to specialist SCI centres have improved health, function and social outcomes, albeit to varying degrees. It

concludes that specialist SCI centres provide the most efficient and effective system for managing persons with SCI and that early admission, life-time surveillance and prompt readmission will ensure the optimum care for people with SCI. Throughout this research indicators show that there are vast potential savings available in health care and social service provision if all people with SCI are treated by specialist SCI centres (Smith, 1999).

Although many factors are related to successful rehabilitation after SCI, the literature (see, for example, Anson et al, 1993; Decker & Schulz, 1985; Kennedy et al, 1995b; Trieschmann, 1988; Wheeler et al, 1996) suggests that social support is influential in the rehabilitation process in assisting people with SCI to make physical and psychological life changes. According to Spencer et al (1995: 57),

The family and significant others are crucial in providing the injured person an emotional climate conducive to the perception of control and positive view of self.

Coming to terms with the permanence of a SCI takes time and requires both psychological and physiological adjustment (Parker, 1996; Spencer et al, 1995). As Decker and Schulz (1985: 741) state:

People who sustain a severe spinal cord injury face numerous adaptation demands. In addition to having problems associated with loss of mobility and sensation, the spinal cord injured person undergoes tremendous psychological stresses.

There have been many theories about adjustment to SCI, with variations on the idea that people pass through a series of stages. The stages generally occur in the following sequence: shock, denial, anger, depression and finally acceptance and adjustment (see, for example, Lindemann, 1981; Jackson Memorial Medical Center, 1998a). Evidence supporting these theories have been equivocal, and research by Hancock et al (1993) indicates that this is not the case up to one year following SCI. Craig et al (1994b: 678) assert that the psychological response to SCI is an individual one, and it may be an oversimplification to claim that time will relieve psychological stress, resulting in lower depression and anxiety levels for all.

Craig et al (1994a: 311) suggest that there may be many factors, other than time, which influence how individuals respond psychologically to the trauma of SCI.

People with a SCI have to come to terms with their change in ability and work through the grief for their disability. This may also include grieving for other people who may have died in the same accident (Sherrard, 1996). In the beginning denial is a common way of coping for many people who sustain a traumatic SCI and also for their family and friends. People often try to deny the seriousness and permanency of a SCI (Jackson Memorial Medical Center, 1998a). Feelings of anger, blame and frustration are also common among patients and their families (Gruar, 1996). Depression and withdrawal can follow feelings of anger and frustration. As patients and their families and friends learn and understand more about how to cope with SCI they tend to accept what cannot be changed or “fixed”. Adaptation gradually occurs and things become more controllable (Guar, 1996; Jackson Memorial Medical Center, 1998a). Sherrard (1989:14) suggests that:

The challenge of adjusting to life after a spinal injury for the person and for the family is greater than most people appreciate... As a nurse I used to think that rehabilitation was complete when discharge from hospital occurred. The period of finding a new pattern of living began at the time of my daughter's accident and this new pattern continues to evolve. One thing is certain, nothing is as it was and there are many challenges on this difficult journey.

Craig et al (1994b) recognise that depression has been considered a universal reaction following SCI and that denial was occurring if a patient was not depressed. Newcombe (1991) suggests that people with SCI may not be as depressed as in the past due to their brighter future and increased opportunities to regain a significant amount of independence. Sherrard (1996: 16) also recognises that:

suicide is the choice of a few with severe SCI. While most people with a spinal cord injury work very hard to make the adjustment, there are those who choose not to live and intentionally commit suicide, sometimes with assistance.



According to Craig et al (1994a) indicators of the lack of long term adjustment to SCI such as suicide, low self-esteem, high divorce rates and drug abuse are areas of increasing concern and illustrates that all people who sustain SCI do not always adjust well.

Successful rehabilitation for people with SCI also includes returning to their previous job or achieving a new level of productivity (Krause & Anson, 1996; Ville & Ravaud, 1996). Returning to work may not be feasible for some people with SCI for a variety of reasons such as medical instability or complications, personal factors including difficulties with equipment and modifications, and also adjustment to disability. This can result in the need for vocational rehabilitation to assist people into more appropriate employment. Traditionally the goal of vocational rehabilitation has been to secure paid employment but this is not the only goal or measure of productivity. The emergence of the independent living movement in the 1970s resulted in many rehabilitation researchers and professionals expanding the concept of “employment” to that of “productivity” (Young et al, 1994). *Productivity* refers to undertaking meaningful activities (including education, group memberships, voluntary work, and homemaking) which do not produce income but give individuals a sense of satisfaction and self-esteem. Most people with SCI should achieve productivity in some form (Young et al, 1994; Jackson Memorial Medical Center, 1998b).

#### **4.2.1 Spinal Cord Injury Services in New Zealand**

In New Zealand there are currently two spinal units; Otara in Auckland and Burwood in Christchurch. The Christchurch Spinal Injuries Unit (SIU) first opened within the Christchurch Public Hospital in 1965 and to cope with growing demand it was transferred to new purpose built facilities at Burwood Hospital in 1979 (Figure 4.2). The Auckland Spinal Cord Rehabilitation Centre was established at Otara in 1976 (Burwood Hospital, 1998).

There are plans for a new comprehensive SIU to be established in Auckland, at Middlemore Hospital.

**Figure 4.2 The Burwood Spinal Injury Unit**



The aim of the Burwood SIU is to enhance individual coping in self-care, mobility and personal hygiene. It has a good reputation and can be seen as a "therapeutic" place of healing.

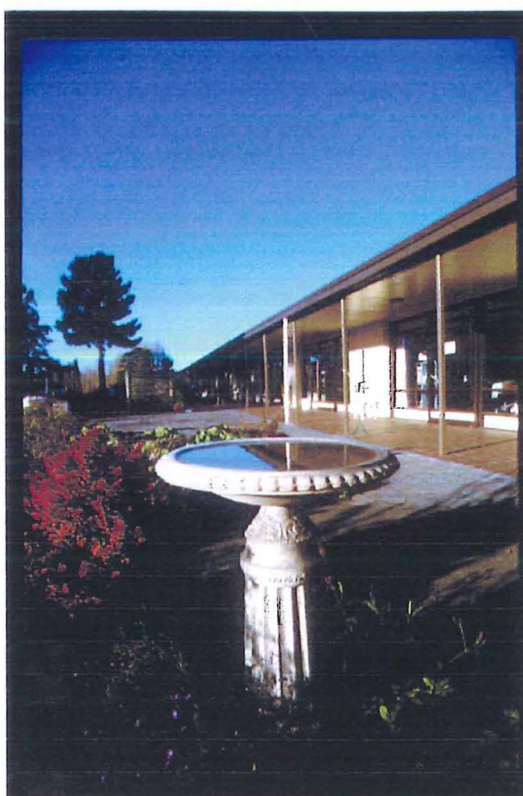
For example, the Tertiary Services Committee (1995: 68) has acknowledged that:

Burwood has a "track record" of good results for its patients... this is based on reported case histories rather than the application of specific quality measures. The more positive regard for Burwood may be related to the fact that it offers a comprehensive service which includes long term follow up and superspecialised services on site, whereas Otara's service is fragmented and long term follow up is not routinely provided.

The Burwood SIU has made many significant advances which have been important for SCI rehabilitation in New Zealand. The first New Zealand tendon transfer surgery to improve hand function in tetraplegics was carried out at Burwood in 1983 and there are now more than 100 people who have had this surgery (Burwood Hospital, 1998). Around eleven people per year receive tendon transfer operations at Burwood and there is a waiting list of approximately a year for this operation (Hirst, 1998b). In 1985, the first New Zealand Brindley implant for bladder control was carried out at Burwood and there are now 16 people with SCI who have had this

surgery. In collaboration with Case Western Reserve University, in the city of Cleveland, USA, the first New Zealand Functional Electrical Stimulation (FES) implants for forearm function in tetraplegics was done at Burwood in 1996 (Burwood Hospital, 1998). There are now three New Zealanders who are recipients of FES implants which have enabled these individuals to regain the use of a paralysed hand and perform ADL independently (Woods, 1999).

Figure 4.3 **The outlook from the Burwood SIU**



The Burwood SIU has a *ward* for acute care, primary rehabilitation and major medical and surgical interventions which looks out to the Spinal Trust garden (Figure 4.3). At the Burwood SIU there is also a *hostel* for out of town patients returning for reassessment, four *self care units* for patients and for relatives, and the *Milner Lodge* which has four houses for patients awaiting permanent accommodation. Burwood Hospital also has a gymnasium (Figure 4.4) where patients receive physiotherapy and a pool (Figure 4.5) for hydrotherapy



sessions. These facilities are important in promoting the healing and rehabilitation for people who sustain traumatic SCI.

**Figure 4.4 The Gymnasium at Burwood Hospital**



**Figure 4.5 The Pool at Burwood Hospital**



The care from the multi-disciplinary team of staff, as well as the services and rehabilitation at the Burwood SIU received a tremendous amount of praise from people who were interviewed. This is typical of the comments that participants made;

"Everything at Burwood is really good... they have got great facilities and services and the staff are just brilliant".

One person said that being at Burwood was like having "twenty mums" looking after you. There appears to be a lack of vocational rehabilitation at the Burwood SIU. This is one area in the rehabilitation process that needs to be addressed, as it is currently being neglected.

### **4.3 Vocational Rehabilitation After Spinal Cord Injury**

Vocational rehabilitation refers to a process of assisting individuals to manage their occupational future by helping them identify their goals and explore a variety of options (Burwood SIU, no date). North (1984) suggests that the three main aims of vocational rehabilitation are the (re)integration of the disabled worker into work according to remaining functions, abilities, skills and aspirations, the efficient use and training of capabilities, and the establishment of safe working conditions so that a disabled worker will not endanger themselves or others.

A variety of factors need to be taken into consideration when taking up work again after a SCI. The first most obvious solution when finding employment for people who have sustained traumatic spinal cord injuries, is to establish whether they can return to the job that they had prior to their injury or if their employer can re-engage them in suitable alternative work (International Labour Office, 1984). If necessary, vocational rehabilitation specialists can help people to select and learn to use assistive equipment they may need to (re)enter the work force. Sometimes a workplace assessment may be required and a person's functional limitations need to be identified. To ensure a safe and timely return to work, an employer and employee must both have access to relevant information about the worker's abilities and limitations at different stages after injury. Workplace modifications and a graded return to work programme may also be needed to help people return to work (Burwood SIU, no date).

In many cases alternative employment options will need to be explored either because it is not practical for some people to return to their previous occupation or because some people have never worked prior to sustaining their injury. Some occupations will be impossible to do after being injured. Others may seem impossible only because they lack the necessary resources and support (Morris, 1989). Vocational rehabilitation specialists can help individuals identify other potential employment and educational options, or other environments where they could be productive. This may require facilitating liaison between the individual and various service providers as well as identifying and implementing any necessary assistive equipment, environmental or task modifications (Burwood SIU, no date).

Lower level occupations expose workers to a higher risk of illness or injury (Berthoud et al, 1993). For example, manual workers, particularly those in the building industry and construction work, are more likely to suffer traumatic SCI in the course of their occupations and are also less likely to be able to return to their former occupations (Gidlow, 1977). A period of voluntary work may be useful to assist individuals in finding a new niche and to allow for the consideration of retraining. Mr Allan Bean (1997: 27), Senior Consultant at the Burwood SIU, suggests that:

There are large numbers of people in the community working at jobs that are below their capacity – *it may take a spinal cord injury to encourage a forestry worker to realize that he should be at university pursuing training of a highly skilled nature.*

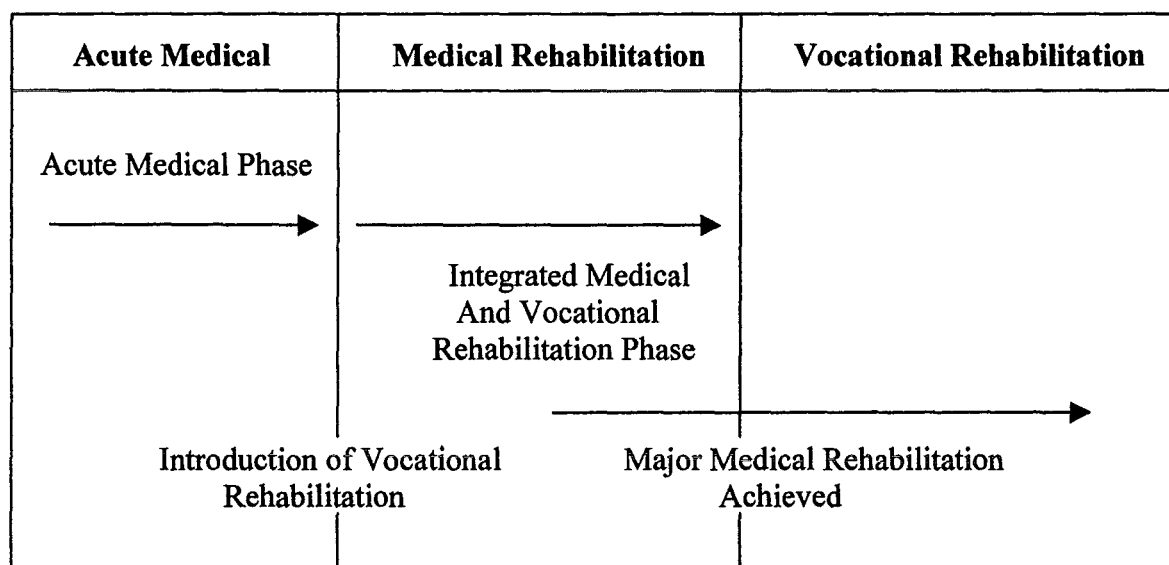
Mr Bean also mentioned the situation where an individual may already have a disability. While the individual may have learnt to compensate for this and be coping well in the workplace a spinal cord injury may complicate the situation and the individual may also have to look at alternative work options (Bean, 1997).

### **4.3.1 The timing of vocational rehabilitation**

A long standing and ongoing debate in the field of SCI rehabilitation has been in regard to the optimum time at which to address vocational rehabilitation. The literature has shown that providing vocational services early on in the rehabilitation process can enhance the ability of people with SCI to gain and maintain employment after their injury. Alfred et al (1987) suggest that the 'window of opportunity' is between 6 and 18 months post discharge, as this is when positive vocational development was found to occur before it began to plateau between 18 to 24 months. They do not rule out vocational rehabilitation being introduced during inpatient stay, although they strongly advise it should not be active in nature but tending towards gathering and sharing vocational information for the purpose of building it into their total rehabilitation plan. Trieschmann (1988) comments on the significant increase in the number of people with SCI in work (and/or training) which occurred when education and vocational guidance was provided early on in the rehabilitation process. Smith (1997) suggests that goal setting may be useful as a means of long range planning and it is also important in preventing the process of identity change before people with SCI stop viewing themselves as workers.

According to the Regional Rehabilitation Services Working Party (1987) it is crucial that a positive attitude towards returning to work is developed early in the rehabilitation process. This is necessary to foster the development of psychological and economic independence and to prevent the adoption of a dependency role, given the fact that the longer people remain on a benefit, the less likely it is they will ever leave it. For this reason, the Regional Rehabilitation Services Working Party (1987) believes that vocational rehabilitation needs to be introduced immediately after the acute medical phase and be integrated with medical rehabilitation from this time, until vocational rehabilitation alone is the major focus (Figure 4.6).

Figure 4.6 Phases in Rehabilitation



(Source: adapted from Regional Rehabilitation Services Working Party, 1987).

When there is a lack of vocational rehabilitation people can often become more established on a benefit system and more likely to acquire a dependency attitude. Not discussing vocational goals leaves individuals vulnerable to 'superstitions' about returning to work, and may lead to beliefs that work is impossible and not a high priority. It is then difficult to assist people to reconceptualise the possibility of returning to work, especially if they have little experience of paid work (Burwood SIU, no date; Regional Rehabilitation Services Working Party, 1987). For some individuals, making specific plans for occupational goals while inpatients may be inappropriate, because of the immediacy of their medical problems. However, raising these issues does give individuals an opportunity to think over and consider their long term future and approach staff as required, even if they say it is too early to contemplate any return to work (Burwood SIU, no date).

To enhance vocational outcomes, it is necessary to foster an expectation that people with SCI can and do successfully return to work. Vocational rehabilitation, therefore, needs to be seen as an integral part of assisting those with SCI to return to as normal a life as possible and that



this is an area to be revisited at various stages throughout an individual's rehabilitation. All staff members have to consistently express this message and staff themselves must be convinced of the appropriateness of this expectation (Burwood SIU, no date).

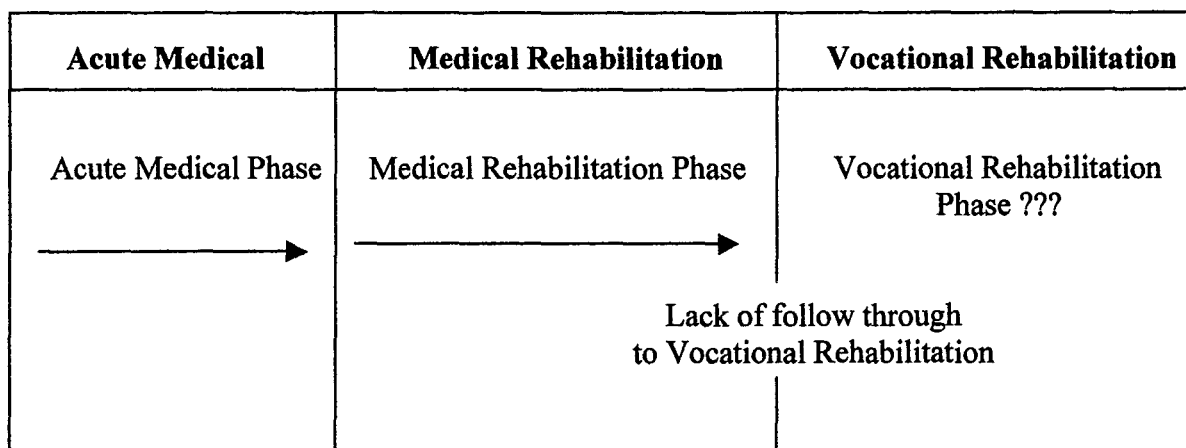
Limited access to vocational rehabilitation services and training options in some areas where people with SCI live can be an issue. People return home when their medical rehabilitation no longer requires hospitalisation but vocational rehabilitation is not always available in the places where people live. It is obvious that smaller centres to which some individuals return may not readily be able to provide specialised vocational rehabilitation assistance to enable individuals to make informed choices about the feasibility of returning to work and retraining options (Regional Rehabilitation Services Working Party, 1987). This gives greater strength to the argument for introducing vocational rehabilitation early on in the rehabilitation process. The young age of many of the individuals sustaining traumatic spinal cord injuries also indicates the long term cost effectiveness and advantages of vocational rehabilitation. This because "some degree of economic independence saves economic resources but also fosters psychological well-being and self-esteem" (Regional Rehabilitation Services Working Party, 1987: 4).

#### **4.3.2 Vocational Rehabilitation at the Burwood SIU**

The focus of the Burwood SIU has been post-traumatic, biomedical and orientated towards discharge. Vocational rehabilitation has moved through a range of phases within the Burwood SIU. While vocational rehabilitation has been used when available it has not been maintained largely due to internal and external restructuring (Burwood SIU, no date). Currently, vocational rehabilitation at the Burwood SIU is not specifically addressed and employment is not established as an expectation for individuals while they are inpatients. The

integration of the medical and vocational rehabilitation in the post-acute phase does not occur at present (Figure 4.7).

**Figure 4.7 Absence of Vocational Rehabilitation at the Burwood SIU**



(Source: adapted from Regional Rehabilitation Services Working Party, 1987).

Historically, it seems that there have been disparate views on the appropriateness of discussing post-discharge goals within the multi-disciplinary team of staff at the Burwood SIU (Burwood SIU, no date). It would appear that some of the staff believe that individuals have enough to cope with and are not ready to face planning for the future while they are adjusting to their SCI. Conversely, others think that post-discharge planning needs to be more aggressively addressed before people leave the SIU.

Mr Bean (1997: 27), Senior Consultant at the Burwood SIU, suggests that:

When I started at the Spinal injuries Unit in 1972 it was expected that people were discharged from the unit on an *Invalid Benefit*. They were encouraged to get out into the community, join the Paraplegic Association, mix with able bodied and return to work if they could. The main drive to return to work was to get off *the poverty* of the Invalid Benefit.

After 1974, all people who sustained spinal cord injuries as a result of personal injury caused by an accident were entitled to cover and rehabilitative assistance from ACC. For many people this

removed the financial necessity of having to return to work. The details of ACC will be discussed at length in the following chapter.

The participants in this study were asked about what vocational rehabilitation, if any, they had received from the spinal injury unit that they were admitted to when they had their injury (Table 4.1). It is important to acknowledge that the individuals' injuries had been sustained between 6 months and 42 years ago and during this time the methods of treatment and rehabilitation will have changed. The majority of the participants (71.4%) said that vocational rehabilitation (that is discussing their future once they leave the spinal injury unit and possible work opportunities) was not discussed. Of the fifty respondents in this group, ten said that they assumed they would return to their previous job. For example, one person said; "I always assumed I was going to go back to my previous job... this gave me something to aim towards".

**Table 4.1 Vocational Rehabilitation received by the Participants**

Vocational Rehabilitation Received	Burwood	Otara	Ward13B	Other**	Total
None / Not discussed	35	6	7	2	50
Discussed with OTs	10				10
Discussed with Social Worker	8		1		9
Helped with computers	4	1			5
Advised not to go back too early	2				2
Discussed with Psychiatrist	2				2
Discussed with Vocational Rehab. Lady	1				1
Discussed with Director of SIU			1		1
Can't Recall			1		1
<b>Total Number of Responses*</b>	<b>62</b>	<b>7</b>	<b>10</b>	<b>2</b>	<b>81</b>

\* There were 81 responses from 70 people (Burwood 52, Otara 7, Christchurch Hospital Ward 13B 9, other 2)

\*\* The 'Other' category included one person who was injured and admitted to a SIU overseas and one person who was not admitted to a SIU because they did not exist when he was injured.

(Source: Access to employment opportunities for people with SCI Survey)

The twenty (28.6%) individuals who did talk about their vocational options and future with either an occupational therapist (OT), the social worker or the psychiatrist, all suggested that these were

only brief discussions. People said that if vocational rehabilitation was discussed it tended to be very briefly and it was very much left up to their own motivation with little or no follow-up.

The participants were also asked how satisfied they were with the vocational rehabilitation that they received (or did not receive) (Table 4.2) and when they thought would be the best time to introduce vocational rehabilitation. Thirty percent of the people interviewed definitely thought that more vocational rehabilitation should been done early on in the rehabilitation process. The respondents made comments like;

"It should be discussed early on once over the acute phase so people know life hasn't come to an end... especially for the younger ones...".

"They should definitely talk about the future and stress that there are still opportunities out there... so people don't give up"

Considering there are computer facilities at the Burwood SIU it is surprising that only four participants said they had received help with computers. While many people thought that more vocational rehabilitation could be done at Burwood they recognised that the process of rehabilitation after SCI is a very individual thing as everyone copes in different ways. This was a typical comment;

"They could do more but people have got to be ready to do it... it needs to be more directed and followed up at reassessments".

Ten people (14.3 percent) said that vocational rehabilitation was not an issue for them. This was because they assumed they would return to their previous job or continue their education, one person was retired, and one female said;

"...they didn't talk about work... it wasn't an issue for me... I had a family to look after".

Even though some individuals did not think that vocational rehabilitation was an issue for them they often thought that it would be beneficial for the "younger ones".

Many respondents commented that it would be useful to know what other people with similar injuries have done vocationally. Numerous participants who were not working said that it

would also be good to talk with other people who have been in the same situation because they know what it is like and can understand. One person suggested that it would be really good to have photographs of people with SCI who are working around the SIU, to inspire others so they know what other people with similar injuries have done and show that life does still go on.

**Table 4.2 Participants' satisfaction with the vocational rehabilitation that they received (or did not receive)**

Satisfaction with Vocational Rehabilitation	Burwood	Otara	Ward13B	Other*	Total
Not satisfied / Should do more	14	2	4	1	21
It is not the right time to discuss work	12	2			14
Wasn't an issue	8	2	3		13
Satisfied / It was helpful	8		1		9
Wouldn't have helped	5	1		1	7
Sort of helpful	3		1		4
Never thought about it	2				2
<b>Total</b>	<b>52</b>	<b>7</b>	<b>9</b>	<b>2</b>	<b>70</b>

\* The 'Other' category includes one person who was injured and admitted to a SIU overseas and one person who was not admitted to a SIU because they did not exist when he was injured.

(Source: Access to employment opportunities for people with SCI Survey)

Twenty percent of the participants did not believe it would be the right time to discuss work when people are inpatients. They felt that people have got to cope with their medical problems and adjusting to home and family environment before contemplating any return to work or retraining. These individuals thought the first or second reassessment would be the best time to begin introducing vocational rehabilitation. Seven people (10%) did not think vocational rehabilitation would have helped them in the early stages of the rehabilitation process. For example, one person said;

"It wouldn't have helped... I was in the wrong frame of mind... I was depressed and had lost my self-esteem...".

Some people who were not working at the time of the interview indicated that they knew what they would like to do in the future and some were working towards their goals. Several participants suggested that people need to have a "return to work action plan" of what they are going to do and the steps that they need to achieve in order to reach their goals. Many individuals while acknowledging that it would not be possible for them to return to their previous jobs had no idea about what they thought they could do or what they would like to do in the future. There were two groups of people who seemed to be most unsure about what they would like to do in the future. Firstly, the individuals with limited work experience who were injured while relatively young (less than 25 years of age) and secondly, those injured later on in life (over 45 years of age) who had mainly worked in manual and physical jobs.

#### **4.4 Chapter Summary**

This chapter has focused on the issue of vocational rehabilitation for people who sustain SCI. The interviews revealed a significant lack of vocational rehabilitation at the Burwood SIU, which reinforces the strong emphasis on the medical and physical aspects of rehabilitation. Clearly, there is a lot more that the Burwood SIU could do with regard to vocational rehabilitation of people with SCI if it had the necessary resources. To improve employment outcomes of people with SCI vocational rehabilitation needs to be introduced early on in the rehabilitation process to foster a positive attitude towards returning to work after SCI. This is clearly important considering the high rates of unemployment for the people with SCI in this study which will be illustrated in Chapter Six.

The next chapter briefly looks at disability in the New Zealand context, to illustrate how responses to disability have changed over time. It then focuses on the vocational rehabilitation and support services for people with SCI within the community which are provided by ACC and Workbridge.

# **CHAPTER FIVE: Vocational Rehabilitation for People with SCI provided by ACC and Workbridge**

## **5.1 Introduction**

The previous chapter examined the provision of vocational rehabilitation for people with SCI at the Burwood SIU. This chapter begins by providing a general overview of disability in New Zealand to illustrate some of the changes in public perceptions and government's responses to disability. Within the New Zealand context, vocational rehabilitation is part of the total rehabilitative assistance provided to the claimants of ACC. All spinal cord injured people, who sustained their impairment as a result of an accidental injury after 1974, have cover and entitlement to rehabilitative assistance from ACC. This chapter looks at the vocational rehabilitation services provided by ACC and Workbridge for people with SCI once they have been discharged from hospital. The vocational rehabilitation, that the participants in this study have received from both ACC and Workbridge and their satisfaction or otherwise with such services will then be examined.

## **4.2 Disability in New Zealand**

Tennant (1996) provides an excellent historical review of the perceptions about disability and changes in disability policies in New Zealand since the colonial period. She shows that in the nineteenth century governments perceived disabled people as one group among the poor and that provision for disability was minimal. Tennant (1996: 8) suggests that:

...the financial support of the disabled came down largely to the family, to charitable aid, and to whatever amounts they could earn through intermittent employment or, as a last resort, busking and begging - at the risk of a vagrancy charge.

Clearly, what is defined as 'disabling' is subject to change, and that responses which one generation regards as progressive and enlightened can be replaced by new orthodoxies.

Tennant (1996: 3) also acknowledges that “there can be no assurance that analyses and solutions proposed in our own times (however well-intentioned and seemingly progressive) will not similarly be rejected in the future”.

War significantly altered the public's perceptions about disability as large numbers of disabled servicemen were discharged into the community. These young previously fit individuals who had acquired disabilities made the greatest impact on public consciousness. The concept of rehabilitation emerged out the First World War, when there was a sense of having to recompense injured soldiers for their sacrifice. State-funded medical treatment and vocational training was provided to soldiers for their military service. A Department of Soldiers' Re-establishment was set up in 1918 (later renamed the Rehabilitation League and now Workbridge). Within five years it gave vocational training to 40,000 disabled servicemen. Government loans were also available to soldiers wanting to establish farms and businesses. Despite this, the focus was still on providing pensions rather than services to disabled servicemen which were determined by rank and level of disability (Tennant, 1996).

Shirley et al (1990: 13) recognise that:

Although social conditions and policies differed from country to country, the post-war economic boom made it possible for Western states to display concern with the distribution as well as production, and with social wellbeing as well as material progress.

In New Zealand the first Labour Government developed social and economic policies which gave the state a strong interventionist role. Labour's welfare policies concentrated on the redistribution of income to provide for those in 'need' (Shirley et al, 1990). The Social Security Act 1938 made comprehensive income support available to all New Zealanders who were unable to work (Bennie, 1996).



By the 1960s the term "rehabilitation" lost its association with ex-service personnel. The social, psychological and vocational aspects of rehabilitation were also stressed as well as the physical methods of treatment. In terms of vocational rehabilitation, organisations such as the IHC, the Crippled Children's Society (now CCS) and the Royal Foundation for the Blind provided sheltered workshops for people with 'severe' disabilities or considerable barriers to employment (Bennie, 1996; Tennant, 1996). The development of sheltered workshops, with their welfare ethos, reflected the common perception that people with profound disabilities would not be able to be employed in the open labour market (Workbridge, 1996a).

The 1970s witnessed two significant pieces of legislation that provided the framework for a considerable increase in the variety of services and supports available to people with disabilities. Firstly, the introduction of the Accident Compensation Act (1972) was significant because it removed costly and time-consuming litigation for those injured by accidents. This provided a comprehensive no-fault system for injury caused by accident which will be discussed in greater detail later in this chapter (Bennie, 1996). Secondly, the Disabled Persons' Community Welfare Act (1975) was important because it delivered a range of provisions aimed at both the individual (to recognise the extra costs associated with having a disability) and at removing barriers to disabled people's participation in society. Among its provisions were loans for motor vehicles and home modifications, the provision of specialised equipment, and the introduction of a building code to promote disabled access to public buildings (Tennant, 1996; Bennie, 1996).

Tennant (1996: 26) suggests that "[t]he new assertiveness among New Zealand's disabled population by the 1980s has been attributed, in part, to the increasing numbers of people who were surviving accidents as adults". The 1981 International Year of Disabled Persons and its associated Telethon helped to promote disability issues onto the political and public stage. In

1983, the Disabled Persons Assembly (DPA) was formed as a grass roots forum and action group. DPA is the only umbrella organisation in New Zealand that has attempted to systematically organise advocacy for and by disabled people operating on a local and national level throughout New Zealand (Bennie, 1996; Tennant, 1996).

In New Zealand, there has been a continued move away from institutional care towards community care with deinstitutionalisation, increased home based support to enable people to stay in their own homes and accessing care through needs based assessment (Ministry of Health, 1998a). The New Zealand 1996/97 Disability Surveys showed that over 95% of people with disabilities lived in the community (Katzehellenbogen, 1998). Community care was associated with policies of 'normalisation' and integration of disabled people into mainstream society. However, such policies came at a time when the welfare state was contracting and many of its earlier responsibilities 'devolving' to voluntary and community groups. The restructuring of the welfare state was to decrease dependency on the state and provide a 'modest safety net' and target assistance to those in 'need' (Cheyne et al, 1997; Bennie, 1996).

In 1992 a government policy document, *Support for Independence for People with Disabilities - A New Deal*, set out goals for disability support services (DSS) (Shipley & Upton, 1992). These were intended to reduce duplication, encourage responsiveness to clients' needs and give value for money. The document not only stated a desire to "improve the quality of life for people with disabilities", but it also recognised the financial realities facing the country (Shipley & Upton, 1992: 25). Services previously subsidised by the state were to be purchased on a market inspired contractual basis. This trend is increasingly characteristic in other public-sector institutions such as ACC. From 1993 to 1995,

responsibility for purchasing DSS progressively moved from the Department of Social Welfare to the Ministry of Health (Ministry of Health, 1998b).

The framework and underlying principles contained in *Support for Independence for People with Disabilities A New Deal* (1992) were built on in the Ministry of Health's (1998) *Disability Support Services Strategic Work Programme*. This report is based on the government's three key goals of maximising independence, effective habitation and rehabilitation, and supporting opportunities to participate. *Supporting opportunities to participate* refers to access to the full range of educational facilities, meaningful work and activity, and recreation and social activities. The budget for Disability Support Services (DSS) is 'ring fenced' to ensure it is not used for other services. However, this report does recognise that "funding for DSS (like all funding) is finite and will stay finite" (Ministry of Health, 1998a: 10). It also recognises that "It is vital that the principles of 'normalisation' of people with disabilities and their inclusion in society are adopted and proactively supported by all key government agencies" (Ministry of Health, 1998a: 21). The government recognises that rehabilitation can involve various forms of interventions as long as these are specific with clear outcome goals over specified time periods (Ministry of Health, 1998a). In other words the government will only support forms of rehabilitation that are cost effective. In New Zealand injury-related disabilities are funded by ACC while age and illness related disabilities are funded by the Health Funding Authority (HFA) (Katzehellenbogen, 1998).

## **5.2 Accident Compensation in New Zealand**

Before 1974, individuals could seek compensation through various means for an injury caused by an accident. Accident victims had the right to sue for damages in court for any injury inflicted as the result of negligence. There was also a workers' compensation scheme and all motorists were

required to have compulsory third party insurance against killing or injuring others. The Criminal Compensation Tribunal also had funds to compensate victims of criminal acts by others. Otherwise, accident victims could depend on modest social welfare benefits (ACC, 1984; 1995; 1997b, Campbell, 1996; Thomson et al, 1998).

Dissatisfaction with the workers compensation benefits led to the establishment of a Royal Commission of Inquiry in 1966, to inquire into and report on workers' compensation. The Commission became known as the Woodhouse Commission and was chaired by Mr Justice Woodhouse (later Sir Owen Woodhouse). In 1967, the Woodhouse Commission reported that the common law system had resulted in considerable unfairness within society, in terms of the benefits received by accident victims. The Commission felt that many New Zealanders were deterred from exercising their right to sue because taking legal action was time-consuming and costly (Thompson et al, 1998; ACC, 1995; 1997b). It concluded that personal injury by accident was a community concern, and, that a comprehensive no-fault scheme would result in fair accident compensation for New Zealanders and would be less of a financial burden on society. The Woodhouse Commission recommended that all motor vehicle injuries should be funded by a premium paid by drivers and owners of motor vehicles. It also recommended that all injuries to earners, whether occurring at work or outside work, should be funded by a flat-rate premium on employers for the cost of injuries to their employees (ACC, no date; 1984).

The Accident Compensation Act 1972, which was based on the recommendations of the Woodhouse Commission, came into operation on 1 April 1974, under the administration of an Accident Compensation Commission. It provided comprehensive, no-fault, 24-hour compensation for all accident-related injuries. Cover was provided without proof of "fault" regardless of how or where the accident occurred, be it at work, at home, on the sports field

or while participating in a recreational activity. In return, the right to sue for damages for an injury caused by accident in court (except for punitive or exemplary damages) was abolished (ACC, no date; 1984; 1995; 1997b; Thomson et al, 1998). The Accident Compensation Scheme (ACS) provided substantial contributions to the costs of medical care and rehabilitation, lump sum payments, earnings related compensation (ERC) and compensation for dependants of fatal injury victims. ERC was calculated at 80% of taxable earnings prior to injury, for the loss of earnings during the period of recovery and rehabilitation. Lump sum payments could be made for permanent loss or impairment of bodily function according to the severity of the injury and for pain and suffering and loss of enjoyment of life (Thomson et al, 1998; ACC, 1995).

The ACS has been reviewed and changed many times since 1972. This has usually been in response to concerns about the escalating costs of the scheme and disputes about the coverage and adequacy of compensation (Thomson et al, 1998). The Government established a Cabinet-Caucus committee chaired by Derek Quigley in 1979, to review the ACS, assess its overall cost and to consider employers' concerns that they were subsidising the cost of non-work accidents (ACC, no date).

In 1982, as a result of Quigley's recommendations, a number of changes were made to the Accident Compensation Act. The rate of compensation payable by employers in the first week after a work accident was reduced from 100% of pre-injury earnings (exclusive of overtime) to 80% (including overtime). The maximum amount of lump sum compensation for the loss of bodily function was increased from \$7,000 to \$17,000. However, the amount payable for pain and suffering and loss of enjoyment of life remained at the 1974 level of \$10,000 (ACC, no date; Thomson et al, 1998, New Zealand Employers' Federation, 1995).

The Government established an Officials Committee in 1986 to undertake another review of the Accident Compensation Scheme. The Committee was made up of representatives from the Department of Social Welfare, the Department of Labour, the Department of Health, Treasury and ACC. Following the publication of the Officials Committee Report in 1987, the New Zealand Law Commission was asked to review the scheme. The chairman of the Commission at the time was Sir Owen Woodhouse. The Commission's report, published in 1987, also proposed some extensive changes to the scheme (New Zealand Employers' Federation, 1995; ACC, no date).

In 1990, the Government appointed a further Ministerial Working Party on ACC because of the continuing escalation in the cost of the ACS. The Working Party was required to review the ACS and examine the possibility of opening up ACC to competition from private insurance companies. It recommended that if private insurers were to compete with ACC then the market should set the rate. The Working Party recognised that private insurers could be selective as to the business that they decide to underwrite (Campbell, 1996). The review resulted in the passing of the Accident Rehabilitation and Compensation Insurance Act (ARCIA) in 1992. This introduced extensive changes aimed at controlling the cost of the scheme for funders which had escalated well beyond all projections since the scheme began (Thomson et al, 1998). For example, expenditure on the ACS increased from \$122 million in 1980 to \$823 million in 1989 and exceeded \$1 billion for the first time in 1990 (New Zealand Employers' Federation, 1995). The ARCIA abolished lump sum compensation and in its place introduced a weekly independence allowance for permanent impairment. It also attempted to define more precisely what injured people could receive and placed greater emphasis on the rehabilitation of injured people (ACC, no date).

The 1992 ARCIA also sought to introduce a work capacity test to assess the ability of long-term claimants to return to work. This would have meant that after twelve months following an accident, if a person had a capacity for work of 85% or more they would cease to be eligible to receive ERC, irrespective of whether or not there are employment opportunities existing for which the person is suited. However, this was not implemented because of the difficulty in developing a test which could determine a percentage capacity for work. The Act was amended in 1996 to allow for a work capacity assessment to be based on the claimant's capacity to engage in work for which he or she is suited on the grounds of experience, and/or education and training. ACC has said that this should only be used when claimants have completed their rehabilitation and still seek ERC (Thomson et al, 1998). The 1996 legislation also placed greater emphasis on rehabilitation and helping injured people return to work and regain their independence. It included the ability for ACC to directly purchase health and rehabilitation services. This has enabled ACC to purchase surgical services from both private and public hospital providers so that injured people can get the elective surgery necessary for them to return to work with the minimum of delay (ACC, no date; 1997b).

In 1998, the Government passed a new Accident Insurance Act, which made significant changes to the delivery of the ACS. The ACC Employers' Account, which provides cover for injuries in the workplace, was opened to competition from 1 July 1999. This has given employers and self-employed people the chance to "shop around" for workplace injury insurance, rather than purchase it from ACC as a monopoly provider. The Government set up a State Owned Enterprise insurer (separate from ACC) called @ Work Insurance to compete with private insurers who can now offer work place insurance. The scheme itself has not changed; it remains 24 hour, comprehensive, compulsory and no-fault. What has changed is that ACC no longer covers employers for their employees workplace injuries. Employers

therefore, have to insure their employees either with a private insurer or with @ Work Insurance (ACC, 1999a; 1999b Department of Labour, 1999).

The future of ACC depends very much on which party comes into power after the general election on 27 November 1999. Ruth Dyson, Labour's ACC spokesperson, has said that the Labour Party will not have private insurers involved in workplace accident insurance. She has argued that "private insurers are more expensive, more litigious, they invite argument we don't want that in New Zealand and they do nothing to reduce workplace injuries" (Interview on the Holmes television programme, 7 July 1999). Labour has said they would go back to the delivery of workplace compensation through one state owned supplier. They are also talking about increasing and allocating lump sums again. The 1998 legislative changes were primarily aimed at bringing a greater level of employer responsibility for injury prevention and rehabilitation. For the first time employers will now have their efforts to maintain safe work places and prevent workplace injuries recognised in the level of premium charged (Department of Labour, 1999). Therefore, employers have a financial reason to be fully committed to the health and safety of the workforce. The new legislative changes have not been in place for long enough to be thoroughly evaluated.

### **5.3 Vocational Rehabilitation After SCI From ACC**

The respondents in this study were asked about what vocational rehabilitation, if any, they that had received from ACC since their injury (Table 5.1). Considering that the aim of ACC is "to reduce the social, economic and physical impact of personal injury on individuals and the community" (ACC, 1997a) it was expected that ACC would have discussed vocational options with all of the participants. Surprisingly, the majority of the people who were interviewed (60.1%) who were entitled to ACC cover, said that they had not discussed the



issue of vocational rehabilitation with ACC. Twelve individuals (17.1%) indicated that vocational rehabilitation had not yet been discussed because they had not fully completed their medical rehabilitation. Six others (8.6%) said that they did not need to discuss vocational rehabilitation with ACC because they already had a job to go back to or their own personal motivation had prompted them to find employment since their SCI. Seven individuals did say that ACC talked about work too much and/or all the time, and they felt that ACC wanted to get them "off their books" as soon as possible. Thirteen of the participants (18.6%) had discussed their goals and retraining options with their ACC case managers. ACC had paid for courses for eleven of the respondents and they had paid for five individuals to get computers. Although ACC will pay for people to do courses they have to be "cost effective". As one person said; "ACC don't want to waste the money for me to do a course if I'm not guaranteed to get a job afterwards...". Three people had received specific individualised assistance from ACC to enable them to work. For example, ACC had paid for an office to be built to enable one person to work from home.

**Table 5.1 Vocational Rehabilitation received from ACC**

Vocational Rehabilitation Received	Frequency (n)
None / Not discussed / Not really	21
Discussed goals / Retraining options	13
Not yet (it's too early)	12
ACC paid for courses	11
ACC talk about work too much / All the time	7
Didn't need to (personal motivation drove things / already had a job to go back to)	6
ACC paid for computer	5
Paid for an office to be built at home	1
Paid for Enable Technology to do a Workplace Assessment so I could work at home	1
Supplied a vehicle, radios & a sheep handling system so I could continue working	1
<b>Total Number of Responses*</b>	<b>78</b>

\* There were 78 responses from 64 participants. Six of the people in this study were not entitled to ACC.  
(Source: Access to employment opportunities for people with SCI Survey)

The individuals were also asked how satisfied they were with the vocational rehabilitation and support that they received from ACC (Table 5.2). It is important to recognise that the subject of satisfaction is multi-dimensional. Ward and Flynn (1994) suggest that satisfaction is an inadequate indicator of service quality if people with disabilities use services unwillingly, and, that they may be cautious in expressing their opinions because of their vulnerability to the benevolence of the service providers. Some respondents appeared to be worried ACC would see the results of this study and participant confidentiality had to be reiterated to ease any concerns. Ward and Flynn (1994) also suggest that some people may report greater happiness, satisfaction or well-being than they really feel in a brief interview, which may disguise distress, deep resentment and other emotions. However, the researcher felt that the individuals in this study benefited from having the opportunity to discuss their dealings with ACC and by having someone listen to and take notice of any of their concerns.

**Table 5.2    Satisfaction with the Vocational Rehabilitation and Support received from ACC**

Satisfaction with vocational rehabilitation and support from ACC	Total
Case Manager(s) have been helpful / supportive	28
ACC don't tell you what you are entitled to	15
You have to chase them up all the time / it takes a long time to get anything done	13
Not satisfied with their lack of understanding of spinal cord injuries	11
Case Managers change too frequently	9
ACC could do more	6
One year for retraining is not enough	3
ACC haven't followed up what they said they would / things have lost momentum	2
Lack of co-ordination between services where I live	2
They are doing as much as they can	2
Couldn't have done anything	1
<b>Total Number of Responses*</b>	<b>82</b>

\* There were 82 responses from 64 participants. Six of the people in this study were not entitled to ACC.  
(Source: Access to employment opportunities for people with SCI Survey)

Some people had nothing but praise for ACC while others made strong criticisms about the service that they had received from ACC. The respondents' satisfaction with ACC appeared to depend on what they expect to "get" from ACC and what people think they need. Forty four percent of the individuals (n=28) who were entitled to ACC, thought that ACC had been helpful and supportive. The following comments are typical of what some of the people said;

"ACC have been really good... a bit slow at times... you have to hassle them to get things done"

"ACC I can't fault them ... some people think that they will get what they want rather than what they need"

"Some people have got the attitude that they deserve everything"

"I've got everything I need and more... they have been very good... it depends on how you approach it some people are very greedy... but you do have to find out what you are entitled to"

In many cases the researcher noted a lack of awareness about the support and assistance that ACC can provide, especially in terms of helping people retrain and return to work. Fifteen individuals (23.4%) specifically mentioned dissatisfaction with the fact that ACC does not tell people what support they are entitled to. They made comments like; "ACC don't tell you what your entitled to... you have to find out for yourself". As one participant said; "It depends on what you know as to what you get". Many respondents said that they had found out about a lot of their entitlements to ACC through other people with SCI while at the Burwood or Otara SIU.

The interviews revealed many inequities in the amount of support that people get from ACC.

For example, one person said;

"I've had heaps of delays waiting for equipment... they don't tell you what you're entitled to you have to find out through friends... I had to pay \$2,000 towards my first chair... if you don't ask they won't tell you..."

Some people (18.6 %) talked about delays in waiting for housing modifications and equipment. In one extreme case one person talked about how it took three years for his housing modifications to be completed. During this time he could not get in and out of his house independently and could not have any privacy when using the bathroom, as there was not enough room to shut the door with his wheelchair. This individual believed these delays had seriously slowed down his rehabilitation and return to work. Therefore, ACC was the primary focus of his life rather than returning to work. A lack of co-ordination between various service providers seems to be a major factor that contributes to many of the delays for housing modifications and equipment that the participants talked about.

The introduction of case management in March 1994 was another important change made to the operation of the ACC scheme (ACC, 1995). Each person with a significant injury becomes the responsibility of an individual ACC case manager. The case manager has the responsibility of working with the injured person and their medical professionals, employer and family to co-ordinate services and support so as to ensure the quickest and most complete rehabilitation (ACC, no date; 1997b). It is essential and critical to have a case manager that is knowledgeable in the area of one's injury or disability in order to have the best possible outcome. The role of the case managers appears to be central to the success of the relationship that the people in this study had with ACC. Some of the respondents' positive experiences with ACC were attributed to the competence of their case manager. For example, one person commented;

"I'm real pleased with the service... they have been extremely good... it does depend on your case manager... mine has a pretty good understanding of spinal injuries"

In contrast, eleven people (17.2%) felt that their case managers did not have a good awareness and understanding of SCI. For example, one individual said;

"...when I was getting my house modified there was a difference of opinion regarding needs and luxuries... life comes down to the basics... case managers don't understand the implications of my injury... They don't realise how much they play god..."

Nine respondents (14.1%) commented that case managers change too frequently. One person said he had had five different case managers in eleven months. Several of the participants also mentioned that their case managers were not very accessible. The following comments are typical of what some of the participants said about ACC case managers;

"ACC case managers change very frequently... it's very pathetic... I've had the last one for three years but before that I was getting a new one about every six months".

"There is no continuity with case managers... they seem to be able to change the rules as they please"

"It depends on your case manager as to what they will fund"

"Now I always have someone to go to ACC case manager meetings with me for moral support... they treat you better if you have someone with you"

Generally, ACC does not undertake to try and find job placements for its' claimants. This is usually left up to the individual claimants or organisations such as Workbridge.

## 5.4 Workbridge

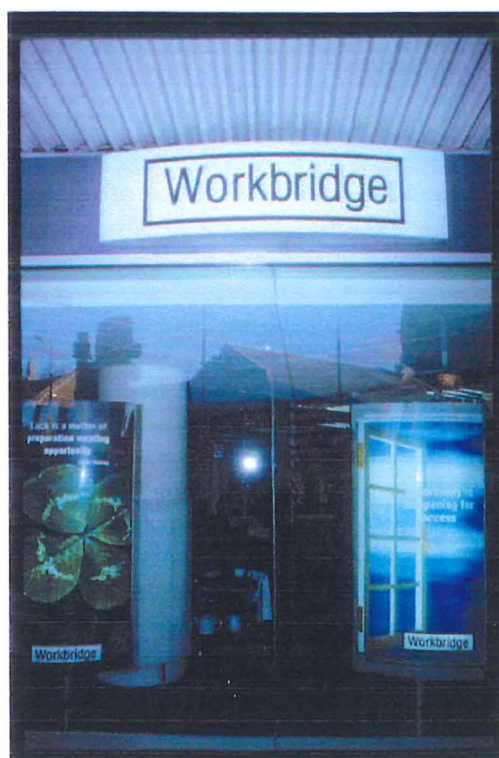
The Rehabilitation League was originally established in 1930 to help alleviate the problems faced by physically disabled war veterans and in 1954 it became the official arm of the government for providing training schemes to physically disabled civilians. It was an incorporated society funded by the government to carry out various programmes of vocational assessment, training, counselling and placement for people having difficulty in finding employment as a result of illness or disability (Tennant, 1999; Newsome, 1987). The Rehabilitation League became an anachronism with only five centres around the country and it had a heavy reliance on outdated assessment techniques and sheltered workshop employment (Bennie, 1996).

In 1990, Workbridge was established to replace the Rehabilitation League. Workbridge is New Zealand's specialist placement service for employers and for people with all types of disability. It is a free service that provides advice, practical support and financial assistance to employers and employees to help with meeting the additional costs of disability so no one is disadvantaged in the workforce (Armitage, 1998a). In 1997, all funding for Workbridge was transferred from the Department of Social Welfare to the Department of Labour (Clarke et al, 1997a). Workbridge are bulk-funded through a main contract with Department of Labour and provides services to other organisations such as ACC on a contractual basis. According to Steve Lavery, Workbridge's marketing manager, about 35-40% of the staff at Workbridge have some form of disability (18<sup>th</sup> Rehabilitation International Congress, 1996). It's board of management consists of three people nominated by the DPA, two employers, Workbridge's Executive Director and representatives of a Minister of the Crown, the New Zealand Employers' Federation and the Council of Trade Unions (Workbridge, 1996a).

Three new *Support Funds* (Training Support, Job Support and Self-Start) were launched in 1994, and the Department of Labour has contracted Workbridge to administer these funds. The funds are to cover the extra costs of disability. *Training Support* is designed to help people with disabilities to improve their skills and prepare them for the workforce. It is available to cover the costs related to disability during work experience, training, or education, examples being additional transport costs, interpreters, a support person, or special equipment. Applicants for training support need to have clearly defined vocational goals and educational intentions. The aim of *Job Support* is to encourage disabled people to move off their benefits and into open employment and integrated workplaces. It covers the costs related to disability and may be used for workplace modifications, a wage subsidy to compensate for lower productivity, special equipment, or to help with transport costs to and from work. *Self-Start* was created to assist people with disabilities to establish their own

business ventures. It aims to provide greater flexibility in meeting individual support needs on becoming self-employed. The funding can be used for things such as equipment required because of the disability, workplace modifications and additional transport costs. Applicants for Self-Start need evidence of a business plan, cash flow projections and a feasibility study is required. The funds are available on a first-come, first serve basis provided that the individuals meet the criteria (Workbridge, 1996a; 1996b; Armitage, 1998c).

**Figure 5.1 The new Workbridge Centre in Christchurch**



Workbridge operates nationally from twenty six Centres throughout New Zealand, seven of which are in the Auckland area (Workbridge, 1996a). On 1 July 1998, Workbridge launched a bold new image which was "designed to reflect the strong trend towards integration for job seekers with disabilities" (Armitage, 1998a: 8). The agency introduced a new logo, a range of promotional material and new "Retail Centres". The Retail Centres are located in high profile locations to help give Workbridge a higher profile and to improve the employment

opportunities for people with disabilities by forcing the issue into the public eye (Armitage, 1998b). The Christchurch Centre was the first to adopt the new look (Figure 5.2). Demand for Workbridge's services has grown steadily over the past few years and there are now waiting lists in some of the Workbridge centres (Workbridge, 1996b).

## 5.5 Vocational Support after SCI provided by Workbridge

Just under half of the people interviewed in this study (47.1%) had heard about Workbridge. These participants had found out about Workbridge in a variety of ways (Table 4.3). Word of mouth was the most common way that people had become aware, followed by through work and referral from ACC. Interestingly, only four individuals had learnt about Workbridge through the Burwood SIU. Many of the people who had not heard of Workbridge were living in places where there were no Workbridge Centres.

**Table 5.3 How people found out about Workbridge**

How people found out about Workbridge	Frequency (n)
Word of mouth	6
Through work	5
Referral from ACC	5
Through Burwood SIU	4
Seen one of the Workbridge buildings	4
TV/Newspaper	3
Through WINZ	2
Through Polytech	1
Through CCS	1
Through the Rehab. Centre in Palmerston North	1
I applied for a job there	1
Can't Recall	1
<b>Total</b>	<b>34</b>

(Source: Access to employment opportunities for people with SCI Survey)



Of the thirty four participants who had heard of Workbridge only ten had actually used Workbridge's services. Three individuals had received training support and one had received job support. Workbridge did organise job placements for two people however, these were both only short term positions. The ten respondents who had used Workbridge were asked how satisfied they were with the service that they received. Generally, people had positive things to say about Workbridge. They made the following comments;

"They helped me get a CV together... which I had never had before... this helped me to identify all the skills I have... they tried to get me a placement but they pushed me too hard... but they did get me motivated"

"They are pretty good... more onto it than ACC"

"My original contact was totally inappropriate due to the person I was dealing with... but the second time was better"

"They have been really helpful... I'm just deciding what course to do"

Workbridge has been criticised for focusing on people with "less severe" disabilities who are easier to place (Bennie, 1996). However, one individual had approached Workbridge to get help setting up a business but he was told that he was "too qualified". Another participant was not very satisfied with the service he had received from Workbridge because they simply gave him a list of the courses that he could do. Two people did not think that the service that they received from Workbridge was appropriate. For example, one person said;

"The Job Map course wasn't appropriate... they were teaching me the wrong things... like grooming, job interviews, CVs... I need to know about jobs for wheelchair people and options for retraining"

## **5. Chapter Summary**

The beginning of this chapter illustrated how responses to disability in New Zealand have changed over time. Disability in the late twentieth century is now seen as having psychological, social and economic, as well as physical dimensions. The remainder of this

chapter discussed the unique accident compensation that New Zealand has for people who suffer injury by accident. There have been many reviews and changes to the accident compensation legislation since it came into operation in 1974.

The majority of the participants (60.1%) who were entitled to ACC said that they had not discussed the issue of vocational rehabilitation with ACC. Although 44% of the respondents thought that ACC had been helpful and supportive, many expressed concern that ACC does not inform people of their entitlements, the length of time it takes to get things done and frequent changes in case managers. Less than half of the people in this study had heard about Workbridge and only ten individuals had actually used their services. There are many ways that ACC and Workbridge could improve the service that they provide to people with SCI which will be discussed in Chapter Nine.

The next chapter describes the employment status of the participants in this study both at the time of injury and at the time of interview. It then discusses some of the factors which positively and negatively affect employment after SCI.

# **CHAPTER SIX: Factors Affecting Employment Outcomes for People with SCI**

## **6.1 Introduction**

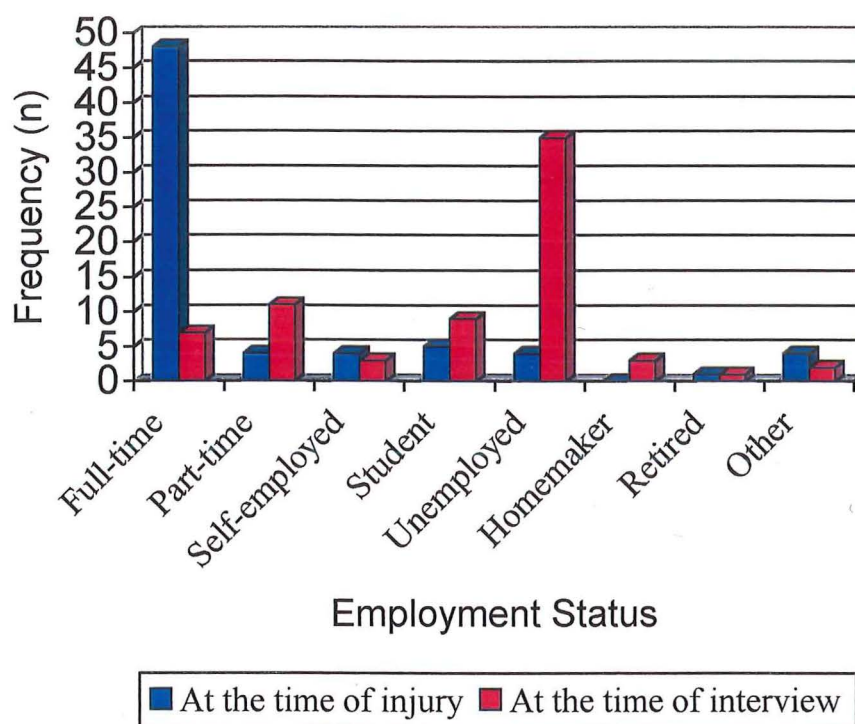
The previous two chapters have looked at the issue of vocational rehabilitation to assist people with SCI return to work. Traumatic SCI undoubtedly, has a profound impact on many areas of an individual's life, one particular one being employment opportunities. A common feature of experiences of people with physical disabilities, is their exclusion from the labour market (Imrie, 1996b). Research suggests people with physical disabilities are more likely to be out of work, unemployed for longer periods and earn less than able-bodied people (see, for example, Kestenbaum, 1996; Simpkins, 1994). This chapter begins by describing and quantifying the employment status of the participants in this study at various points in time. It then discusses some of the factors which affect employment after SCI.

## **6.2 Employment After Spinal Cord Injury**

The existing literature regarding employment after SCI details a diversity of return to work rates. For example, Trieschmann (1988) reviewed more than twenty studies on employment after SCI and found that the employment rates ranged from 13-48 percent. Similarly, Murphy and Athanasou (1994) in their review of employment after SCI found that the employment rates varied from 13-69 percent. The variations in employment rates following SCI are not surprising considering the that samples often differ with respect to sampling procedures, methodology and sample characteristics (for example, age, level of injury and time since injury). The outcomes can also vary greatly depending on the definition of employment that is used, as some studies include productive activities such as homemakers and/or students (Krause, 1992; Krause and Anson, 1996; Young et al, 1994).

This study has attempted to ascertain the employment status of seventy people with traumatic spinal cord injuries in New Zealand (Figure 6.1). For the purpose of this study *employment* is defined as paid work (either full-time or part-time) and includes people who are self-employed and casually employed. At the time of injury 83% of the respondents were employed versus only 32.9% at the time of interview. Of the twelve individuals who were not employed at the time of injury, seven had worked at some stage before injury and five were full-time students. Therefore, 93% of the participants had worked at some stage before sustaining their SCI. The respondents' job duration before injury ranged from one week to forty six years. Half of the people who were interviewed had been working for ten or more years before their injury and twelve had worked for over twenty years.

**Figure 6.1 The participants' employment status at the time of injury and at the time of interview**



Clearly, there was a significant reduction of people working full-time from 68.6% (n=48) at the time of injury to 10% (n=7) at the time of the study (Figure 6.1). However, there was an increase in participants working part-time, from 5.7 percent (n=4) at the time of injury, to 15.7% (n=11) at the time of the study. Two people used to work full-time but had cut back to part-time because their health had deteriorated. Four respondents were self-employed (three full-time and one part-time) at the time of injury and three were self-employed part-time at the time of the study. At the time of interview two individuals were working part-time as well as studying part-time. Although thirty five of those interviewed (50%) were unemployed at the time of the study only three individuals said that they were actually looking for work. The "other" employment status category included four participants at the time of injury (two were employed casually, one was on holiday and due to start full-time employment and one was a seasonal worker about to recommence working) and two individuals were employed casually at the time of the study. Half of the people in this study have undertaken some voluntary work (that is work that they have not been paid for) since their injury. People's involvement in voluntary work included things such as helping out at school, coaching wheelchair tennis and basketball, being on a church committee, being the president for a rugby club, being involved in Lions and a Roundtable Service Club, and being the secretary and treasurer for a charitable trust.

**Table 6.1    Return to previous job after injury**

Return to previous job after injury	Frequency (n)	Percent (%)
No	55	78.6
Yes and still working there	8	11.4
Yes but no longer working there	5	7.1
Assume they will return to their previous job eventually	2	2.9
<b>Total</b>	<b>70</b>	<b>100</b>

(Source: Access to employment opportunities for people with SCI Survey)

Forty percent of the participants had been employed at some stage since their injury. However, at the time of the study, only 32.9% were working. The majority of the respondents (81.5%) have not returned to the job that they had at the time of injury (Table 6.1). Thirteen individuals (18.5%) did return to their previous jobs and at the time of the study eight (11.4%) were still working in the same job that they had before their injury. Two people assume that they will eventually return to their previous jobs once their health and physical strength improves. Of the twelve persons whose spinal cord injuries were caused by work accidents only one had subsequently returned to the same job that he had at the time of injury.

**Table 6.2 How the participants who were working obtained their jobs**

How participants got their current job	Frequency (n)	Percent (%)
Worked there prior to injury	8	34.8
Through a friend/personal contact	6	26.1
Self-employed and established business/position after injury	3	13.1
Through a newspaper advertisement	2	8.7
Promotion	2	8.7
They approached me to apply for a job	1	4.3
ACC referral	1	4.3
Total	23	100

(Source: Access to employment opportunities for people with SCI Survey)

The twenty three people who were in paid employment at the time of interview were asked how they obtained their current jobs (Table 6.2). Eight indicated that they returned to the job they had prior to their injury, while a further six got their jobs through a friend or personal contact. Only two people had obtained their jobs through newspaper advertisements. Interestingly, none of the participants who were working at the time of interview gained employment as the result of Workbridge placements.

Table 6.3 Occupation at the time of injury and at the time of interview

Occupational Classification	At Injury		At Interview	
	n	%	n	%
Legislators, Administrators and Managers	0	0.0	0	0.0
Professionals	2	3.4	4	17.4
Technicians and Associate Professionals	4	6.9	5	21.8
Office and Customer Service Clerks	4	6.9	5	21.8
Service and Sales Workers	11	17.2	4	17.4
Agricultural and Fisheries Workers	5	8.6	1	4.3
Trade Workers	11	17.2	3	13.0
Plant and machine Operators	4	6.9	1	4.3
Elementary Occupations	19	32.8	0	0.0
Total	58	100	23	100

(Source: Access to employment opportunities for people with SCI Survey)

For the purpose of this study occupations were classified using the *New Zealand Standard Classification of Occupations* (NZSCO 95) (Appendix G). The occupations of the participants prior to injury were wide ranging covering all of the occupational categories except legislators, administrator and managers (Table 6.3). Interestingly, while 32.8% of the respondents, worked in elementary occupations (such as forestry and the freezing works) at the time of their injury, none worked in such occupations when they were interviewed. This is not surprising because elementary occupations are more likely to require physical strength and physically disabled people are therefore less likely to return to such occupations. Although fewer people were working following their injury, a greater proportion worked in skilled occupations (for example, teaching and psychotherapy) (Table 6.3).

### 6.3 Factors Affecting Employment After SCI

There are numerous factors that have been identified as affecting employment after SCI. These include the following education, age when injured, level of injury, gender, pre-injury employment experience, job seeking effort, geographic region, motivation to work, psychological adjustment, rehabilitation services, and the issue of bowel and bladder care

(see, for example, Murphy & Athanasou, 1994, Burnham et al, 1996; Crisp, 1990). Previous studies have often tried to explain vocational outcomes in terms of characteristics of individuals with SCI but have given little attention to environmental variables such as employer attitudes, rehabilitation methods and financial disincentives to employment (Crisp, 1990). According to Ville and Ravaud (1996) studies on factors affecting employment following SCI sometimes have ambiguous results and generally weak and non-predictive relationships which demonstrates the complex and multi-dimensional nature of return to work for this group of people.

### 6.3.1 Education

Education has been one of the most frequently reported factors associated with employment after SCI (see, for example, Alfred et al, 1987; De Vivo et al, 1987; Krause, 1992; Castle, 1994; Young et al, 1994; Ville & Ravaud, 1996; Krause & Anson, 1996). Those with a high level of education are more likely to return to work than those with a low level. Crisp (1990) suggests that spinal cord injured people with higher education levels are less likely to perform manual occupations and therefore have a better chance of returning to work.

**Table 6.4 Highest educational qualification gained prior to SCI**

Highest educational qualification	Frequency (n)	Percent (%)
None	28	40.0
School Certificate	13	18.7
Sixth Form Certificate	11	15.7
Bursary	1	1.4
Certificate / Diploma	8	11.4
Trade Certificate	8	11.4
University Undergraduate Degree	1	1.4
University Postgraduate Degree	0	0
Total	70	100

(Source: Access to employment opportunities for people with SCI Survey)



In this study education level was measured by the highest qualification gained at the time of injury (Table 6.4). Over one third (35.8%) of the respondents had school qualifications and 24.2% had post-school qualifications. However, only one person had a university degree. It is interesting to note that 40% of the participants had no educational qualifications compared to 32% nationally (1996 Census) (Katzehellenbogen, 1998). As 83% of the individuals were working at the time of injury this suggests that many had jobs which did not require formal educational qualifications.

The correlation between education and return to work after SCI was not statistically significant ( $p>0.05$ ) in this study. However, the individuals with no qualifications at the time of injury had the lowest employment rates at the time of interview (17.9%). Surprisingly, the highest employment rates occurred for the participants with school qualifications (48%) rather than for those with post-school qualifications (35.3%) (Table 6.5).

**Table 6.5 Level of education at injury and employment at interview**

Level of education at injury	Number of participants	Employed at interview	
		n	%
No qualifications	28	5	17.9
School qualifications	25	12	48.0
Post-School qualifications	17	6	35.3

(Source: Access to employment opportunities for people with SCI Survey)

According to Krause (1992), education is one of the best predictors of return to work after SCI, especially if it has taken place post injury. Further education or training is often seen as one way to improve ability to find work (Society for Research on Women, 1994). At the time of interview over half (51.4%) of the respondents in this study had undertaken some further education or training since their injury, and four individuals had undertaken two forms of further education (Table 6.6). The majority of the people (47.2%) who had done some further

education since their injury had done a computer course, and five were putting their energy into acquiring new qualifications. Many people (51.4%) expressed concern about lacking the skills and qualifications to return to work (Table 6.11) and the majority (74.3%) said they would like to do some further education and/or training in the future.

**Table 6.6 Further education or training since SCI**

Education or training since injury	Frequency (n)
Computer Course	17
Certificate / Diploma*	5
Polytech Courses	4
University Undergraduate Degree**	3
University Postgraduate Degree***	3
Business Courses	3
In House Training	2
Welding Course	2
Secretarial Course	1
Total	40

\* Includes three people who were studying towards a certificate or diploma at the time of interview

\*\* Includes one person who was studying towards a university degree at the time of interview

\*\*\* Includes one person who was studying towards a post-graduate degree at the time of interview

(Source: Access to employment opportunities for people with SCI Survey)

### 6.3.2 Age when injured

Previous studies have found that age when injured is one significant factor related to return to work after SCI, with younger people being more likely to return to work than older people (see, for example, Castle, 1994; De Vivo et al, 1987; Krause, 1992; Taricco et al, 1996; Ville & Ravaud, 1996). However, Young et al (1994) did not find age when injured to be significantly related to return to work following SCI. Krause and Anson (1996) speculate that people who sustain spinal cord injuries after fifty years of age will only return to the workforce if they can return to their pre-injury occupation. Crisp (1990) suggests that lower

return to work rates for older persons may be the result of reduced power of adaptation and reluctance of employers to (re)employ persons with a limited working life. Similarly, Krause and Crewe (1991) have suggested that the effects of SCI are more devastating to older people as they are more likely to experience poor adjustment post-injury in many areas of their lives. As a consequence they may opt for early retirement. However, none of the people in the current study opted for this choice.

In this study the relationship between return to work and age when injured was not statistically significant ( $p>0.05$ ). The people who were injured before 25 years of age had the highest employment rate at the time of interview (41.9%) in contrast with those in the 25-40 age group who had the lowest rate of employment when interviewed (20.8%) (Table 6.7).

**Table 6.7 Age when injured and employment at interview**

Age when injured	Number of participants	Employed at interview	
		n	%
< 25 years	31	13	41.9
25 to 40 years	24	5	20.8
> 40 years	15	5	33.3

(Source: Access to employment opportunities for people with SCI Survey)

The reasons for the low rate of return to work at the time of interview in the 25-40 age group are not clear. Although it is interesting to note that the participants who were injured before twenty five years of age had the highest rate of further education or training since injury (67.7%), while those aged over forty years when injured had the lowest rate of further education or training since injury (46.7%) (Table 6.8). Several participants said that they thought they were "too old" to retrain.

**Table 6.8 Further education since injury and age when injured**

Age when injured	Number of participants	Further education since injury	
		n	%
< 25 years	31	21	67.7
25 to 40 years	24	12	50.0
> 40 years	15	7	46.7

(Source: Access to employment opportunities for people with SCI Survey)

### 6.3.3 Time since injury

There is a paucity of research related to the long-term employment rates among people with SCI. Krause (1992: 167) states that "employment rates dramatically improve with increasing time since injury" and De Vivo et al (1987) cite a small increase in employment rates as time since injury increased. However, Young et al (1994) did not find time since injury and return to work to be statistically significant.

**Table 6.9 Time since injury and employment at interview**

Time since injury	Number of participants	Employment at interview	
		n	%
< 2 years	22	5	22.7
2 to 10 years	30	6	20.0
> 10 years	18	12	66.7

(Source: Access to employment opportunities for people with SCI Survey)

In this study those who had been injured for over ten years had the highest rate of employment (66.7%). It is interesting to note that four of the six non-ACC recipients were employed at the time of interview (two full-time and two part-time). The low rate of employment for the participants who had been injured for less than two years (22.7%) is not unexpected as it is often thought to take several years to adjust to SCI (see, for example,

Castle, 1994; Crisp, 1990). It is surprising how similar the employment rates were for the people who had been injured for 2-10 years (20%) and those who had been injured for less than two years (22.7%) (Table 6.9). The reasons for this are not clear although it is important to recognise that it takes time to physically adjust and regain strength after SCI. Medical problems may also persist and affect return to work after SCI.

### 6.3.4 Level of injury

It is often expected that level of injury will affect return to work for people with SCI. Some studies have found that the higher the level of injury the less likely people are to return to work. That is, paraplegics are more likely to return to work than tetraplegics (see, for example, Castle, 1994; Krause, 1992; De Vivo et al, 1987; Burnham et al, 1996). However, level of injury has not consistently been associated with return to work (see, for example, Taricco et al, 1992; Crisp, 1990; Young et al, 1994). Crisp (1990) does suggest, however, that level of injury may influence the types of jobs undertaken by people with SCI. Burnham et al (1996) explored the effect of level of injury, functional and physical factors to employment outcomes. They found positive employment outcomes to be more strongly correlated to a history of self-employment, and with having been employed or actively searching for work in the four weeks prior to injury.

**Table 6.10 Employment rates at the time of interview in relation to level and type of injury**

Level and type of injury	Number of participants	Employed at interview	
		n	%
Complete Tetraplegic	13	4	30.8
Incomplete Tetraplegic	20	6	30.0
Complete Paraplegic	19	8	42.1
Incomplete Paraplegic	18	5	27.8

(Source: Access to employment opportunities for people with SCI Survey)

There was no statistically significant relationship between level of injury and return to work in this study ( $p > 0.05$ ). In general, participants with complete paraplegia had the highest employment rate (42.1%) at the time of interview, whereas those with incomplete paraplegia (27.8%) had the lowest rate of employment (Table 6.10). It is interesting to note that four of the participants with complete tetraplegia were employed which illustrates that people with 'severe' SCI are capable of working. This may suggest that motivation is more important than 'severity' of disability. Only two of the seventeen walkers were employed at the time of interview (one person with incomplete tetraplegia and one with incomplete paraplegia). Gerhart et al (1992: 286) suggest that:

...it is clear that good neurological recovery alone does not ensure that there will be no post injury problems. In fact the problems reported by individuals with minimal spinal cord injuries were strikingly similar to those of much more severely disabled counterparts.

Some of the individuals in this study who were able to walk still had a variety of medical problems including chronic pain and bowel and bladder problems. They often commented that they got very tired and could not stand for long periods of time which affected their return to work.

### **6.3.5 Gender**

Geographic research has shown that "women tend to adapt their paid employment to accommodate traditional gender divisions within the home" (Bondi, 1993b: 242). Pratt and Hanson (1991) have shown how day-to-day, space-time constraints influence women's domestic labour, their job search and labour force participation. Berthoud et al (1993) suggest that women are more likely to work part-time especially if they have children to look after and a husband's income to fall back on. However, the increasing proportion of single parent families means fewer women have a partner's income to fall back on. Lonsdale (1990) suggests that a number of women do voluntary, unpaid work either as a stepping stone to

getting employment or as an alternative when they cannot get work. In New Zealand, women do most of the unpaid housework and childcare and are concentrated in a narrow range of predominately female occupations. On the other hand, men are involved in a wider range of occupations and are more likely to be in administrative and managerial jobs than women (Du Plessis, 1994).

Both Young et al (1994) and Ville and Ravaud (1996) found that men were twice as likely to be in paid employment after SCI compared to women. Conversely, Krause and Anson (1996) found that Caucasian women had higher employment rates after SCI than men (although this did include the role of homemaker). The more entrenched a person was in their pre-injury job, the greater the difficulty they have in shifting careers after SCI which is the rationale provided by Krause and Anson (1996) as to why men, even though they were working at the time of injury, have lower return to work rates after SCI. This is because men tend to be socialised to have a narrow range of social roles and therefore employment is central to their identity whereas women's social roles are usually more diverse.

In this study, although a smaller proportion of women than men (70% females versus 85% males) were working at the time of injury, a greater proportion of women were at the time of interview (50% versus 30%). However these findings, were based on a sample of only ten female and sixty male participants and were not statistically significant ( $p > 0.05$ ).

### **6.3.6 Labour Market Factors**

The legislative and economic climate can also alter the conditions in which people with SCI look to obtain and retain employment (Crisp, 1990). For example, De Vivo et al (1987) conducted a retrospective seven year follow up study of 154 American subjects, who were treated between 1973-1979 at the same Alabama hospital. They found that people with SCI

had a low employment rate (19%) and this was partially attributed to the high levels of unemployment in Alabama at the time. De Vivo et al (1987) also commented that seven years might be too short a time frame to follow up employment outcomes.

Internationally, the level of employment of people with disabilities is considerably lower than the employment rate of the general population (Smith, 1999). The National Health Committee (1998: 8) suggested that, "[w]orkplace restructuring and job insecurity have been a predominant feature of the working environment in New Zealand over the last decade". The assumptions of having a "job for life" has been replaced by acceptance of the need to be adaptable and that employment is for fixed periods of time (Clarke et al, 1997). In New Zealand disabled people are much less likely to be working. The 1996/97 Disability Surveys found that only 37% of disabled people were in paid employment compared to 66% of the able-bodied population (Statistics New Zealand, 1998). According to the Household Labour Force Survey, the seasonally adjusted unemployment rate was 7.0% in the June 1999 quarter. This is the lowest unemployment rate since December 1997 and has decreased from 7.6% a year ago and from 7.2% in the March quarter (Statistics New Zealand, 1999). The trend of increasing part-time work (Bruce, 1999; Barnes et al, 1998) means there should be more employment opportunities for disabled people (Johns, 1991).

### **6.3.7 Where people live**

There are considerable geographic, ethnic and age differences in unemployment rates (National Health Committee, 1998). At the 1996 Census the highest levels of unemployment were in the East Cape (11.5%) and Northland (10.8%) regions of the North Island and the lowest were in the Tasman (4.2%) and Southland (5.5%) regions of the South Island. Where people live clearly affects their employment opportunities. The majority of participants



(77.1%) did believe that there are jobs out there (Table 6.11). However, one person commented that;

"Taupo is a pretty small place and there are not many jobs and not many opportunities for people in wheelchairs... it depends on forestry and tourism".

Interestingly nine people had moved to Christchurch since their injury. They came from Queenstown, Greymouth, Nelson, Tauranga, Samoa, Akaroa, Dunedin, Auckland and Wellington. The main reason for moving to Christchurch was to be closer to the Burwood SIU due to the lack of services or people with a good understanding of SCI where they lived previously. Other reasons included increased job opportunities, improved accessibility compared to where they previously lived and also to be closer to family.

### **6.3.8 Ethnicity**

The 1996 Census indicated that Maori, Pacific Islanders and young adults had much higher rates of unemployment than the general population (National Health Committee, 1998). In this study 86.4% of the fifty-nine European participants were working at the time of injury compared with 72.7% of the eleven non-European participants. At the time of interview 39% of the European individuals were working and none of the non-Europeans were working. This was statistically significant ( $X^2 = 0.015$ ,  $p < 0.05$ ) however, because 25% of the cells had expected counts less than five chi-square may not be a valid test.

### **6.3.9 Motivation to work**

The vast majority of people with disabilities have capacities that would enable them to be employed in some way. Fatigue can be a major factor affecting people's return to work as it affects ability to work "normal" hours (Croxe, 1984). Full-time employment is not always feasible for people with SCI. The majority of the participants in this study said that they

definitely wanted to work (78.6%) and that they have the confidence to work (70%). Although the majority of persons interviewed said that they were not afraid of injuring or harming themselves by working (70%), many (45.7%) felt very uncertain about their ability to do a full day's work (Table 6.11). For example, one individual said; "I can't do transfers and have to rely on other people... No way can I do a 9 to 5 job". Many people commented that if they did work it would have to be part-time.

**Table 6.11 Issues and concerns with regard to employment**

Issues and concerns	A lot		A Little		Never	
	n	%	n	%	n	%
There are no jobs out there	5	7.1	11	15.7	54	77.1
Concern about losing entitlement to ACC*	21	32.8	19	29.7	24	37.5
Uncertain about ability to do a full days work	32	45.7	21	30.0	17	24.3
Not having the confidence to work	7	10.0	14	20.0	49	70.0
My doctor said I can't go back to work	2	2.9	7	10.0	61	87.1
Lacking the skills & qualifications to work	11	15.7	25	35.7	34	48.6
Afraid of reinjury/harming myself by working	8	11.4	12	17.1	50	71.4
Not wanting to work	15	17.1	10	14.3	55	78.6
Worry about bowel and bladder control	18	25.7	25	35.7	27	38.6
Having to work for financial survival	11	15.7	18	25.7	41	58.6

\* Six of the participants (8.6 %) were not entitled to ACC  
(Source: Access to employment opportunities for people with SCI Survey)

It is also important to acknowledge that medical problems associated with SCI (for example, urinary, pain, skin and injury site complications) can greatly influence the participants' quality of life and affect their ability to work. Over half of the people interviewed (61.4%) said they worried about the issue of bowel and bladder control with regard to working (Table

6.11). Some individuals did say that the issue of bowel and bladder control used to be a concern but it had become more controllable over time. Morris (1989) suggests that whether or not people with SCI have the same energy and/or incentive, as before being paralysed, to participate in the paid labour force is another important limiting factor.

### **6.3.10 Financial Disincentives to work after SCI**

According to Crisp (1990), financial disincentives are a major barrier to employment for some individuals. The Disability Sector Vocational Coalition (1997) recognised that the economic benefits of participating in paid employment for people with disabilities are minimal. This is because of abatement systems and the fact that income may be offset by the increase of work related disability costs (see, for example, Hasler, 1993) or having to face stand down periods should their employment not work out or they lose their jobs. Both Krause (1992) and Trieschmann (1988) comment on the need to remove financial disincentives to improve employment rates for people following SCI.

In New Zealand, ACC contributes to the financial disincentive to work for people with SCI. ACC Earnings Related Compensation (ERC) is awarded at 80% of what a person earned before their injury. The rate at which it is granted is not means tested, and it is independent of any partner's income. This means that people receiving ERC from ACC often have higher incomes than people on the unemployment or invalid's benefit (Pernice, 1998). Over half of the participants (58.1%) in this study said that they do not have to work for financial survival (Table 6.11). As one person who was receiving ERC from ACC said, "You learn to adjust to 80% of your earnings... we have paid off our house and car so we are doing OK". However, over half of the respondents (62.5%) who were entitled to ACC did express concern about losing entitlement to ACC which may have increased their motivation to undertake further

education and/or training in the hope of getting a better job in the future. The six individuals (8.6%) in this study who were not entitled to ACC, often made comments about what it was like before ACC was introduced such as;

"It was assumed you would carry on... the assumption was that you would have to work because there was no ACC... although some did get insurance compensation".

"You do feel a bit jealous compared to what they get now... everything is handed to them on a plate... the incentive isn't there to work anymore".

### **6.3.11 Transport**

The ability of a person with SCI to drive their own motor vehicle, or be driven by others (when the physical limitations of SCI make driving difficult), is another predictor of their employment status after injury and a key variable with regard to independence and social activity (Smith, 1999). Paraplegics are more likely to be able to drive which gives them freedom and increases independence, and thus provides them with a greater range of employment options (Smith, 1997). People with SCI who are not able to drive are dependent on others, and lack the spontaneity of being able to go out whenever they want to and this may increase social isolation (Seymour, 1998). In this study, twenty five of the seventy participants (35.7%) could not travel independently and sixteen of them (22.9%) said that they could not get out when they wanted to.

## **6.4 Chapter Summary**

This chapter has shown the dramatic changes in employment status for a sample of seventy people with SCI in New Zealand. Although 83% of the participants were employed at the time of injury only 32.7% were working when interviewed. This employment rate after SCI is within the range of previous overseas studies. The ability of people with SCI to work is a function of a variety of factors such as age when injured, education, level of injury, gender,

time since injury and financial disincentives along with a range of medical, vocational and motivational factors. The importance of these various factors appears to vary between individuals, which reflects the complexity of employment after SCI.

The next chapter will examine some of the main barriers to accessing employment opportunities specifically for people with SCI. It will look at the main reasons why so many of the participants in this study were not working and the obstacles they see standing in their way of obtaining employment.

## **CHAPTER SEVEN: Barriers to Accessing Employment Opportunities for People with SCI**

### **7.1 Introduction**

The previous chapter illustrated some of the main factors affecting employment after SCI. Research has noted that people with disabilities generally have greater difficulty obtaining and retaining employment and are more likely to be unemployed or underemployed compared to able-bodied people (Studholme, 1994; Employment and Skills Formation Council, 1994). This chapter examines some of the main barriers to accessing employment opportunities specifically from the perspective of people with SCI. It will discuss the literature on employers' perceptions of, and attitudes towards, employing people with disabilities. It will also look at ways of overcoming some of the barriers and how new technology can enable disabled people to gain access to new working environments and employment opportunities.

### **7.2 Barriers to Accessing Employment Opportunities**

The poor representation of people with disabilities in the labour market is due to a variety of factors. The Employment and Skills Formation Council (1994: 7) suggested that:

...it is often not that the disability restricts participation in employment and society by people with a disability it is the social, cultural, physical, and economic barriers that exist within the employment environment and society.

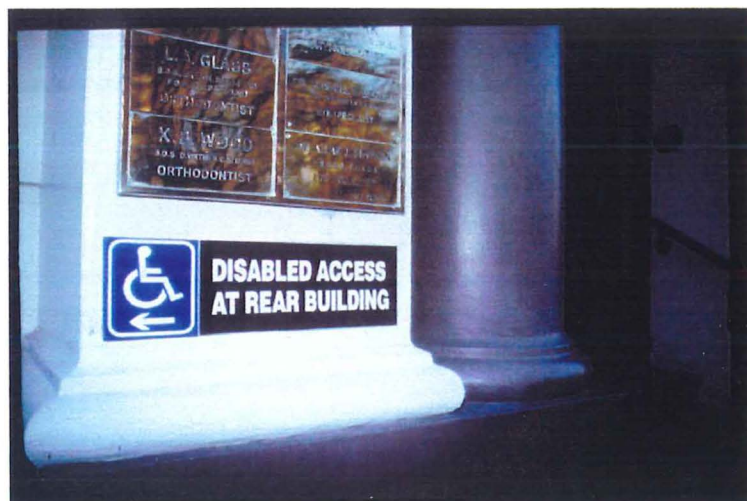
Although the medical problems associated with SCI are unique, the barriers to employment faced by people with SCI are often common to disabled people in general. It is important to acknowledge that people with SCI are not a homogeneous group and their capabilities, needs and the barriers they face are not necessarily the same. The main barriers to employment after SCI that have been identified in the literature are; insufficient education and training,

financial disincentives, pain, vocational interests not being congruent with physical capabilities, physical barriers and employer attitudes (Crisp, 1990).

### 7.2.1 Physical Barriers

Mobility is one important factor in peoples' ability to participate in society. It is taken for granted that people are able to move freely in space. However, this is not the case for many wheelchair users as they are often prevented from reaching their full potential because of poor information, signage, urban planning and design (Matthews and Vujakovic, 1995). Lack of physical access to the built environment was the leading socially disabling factor identified by over half of the 800 people with SCI in Smith's (1999) study. The environment is therefore another negative factor impacting on the successful return to work after SCI. The inaccessibility of many workplaces for people who use wheelchairs is a clear example of how the labour market excludes people, by the assumptions it makes about what constitutes a "normal" worker (Taylor, 1996). Krause (1992) believes that environmental accessibility (for example, building access, transport as well as appropriate service provider access) is necessary to enhance employment outcomes for people with SCI.

Figure 7.1 **Physical Access to the Built Environment**



In all areas of New Zealand there are numerous examples of physical barriers and places that people in wheelchairs cannot enter (or face significant difficulty entering), despite the 1991 *Building Act Code of Compliance* (Figure 7.1). This code is only applicable to new public buildings and extensions built after February 1992 (Lawrence, 1998). The people with SCI who were interviewed in this study told the researcher about a variety of places that they could not get into without assistance, which made their life difficult. Several individuals who had been injured for a number of years did comment that accessibility has improved.

The urban environment is shaped by public policies and these reflect social attitudes and values (Imrie, 1996b). Modifying the built environment and enhancing mobility by providing wheelchair access at doorways, curbs, ramps and toilets accommodates people who have mobility impairments. Using a wheelchair does impose some limitations but these can usually be overcome by providing a means of access to and around the workplace (Kettle & Massie, 1986). The introduction of low floor buses to Christchurch is an example of modifying the design and operation of public transport to enhance barrier free movement. According to Butler and Bowlby (1997: 412),

A physical environment which enables the presence of disabled people in public space may stimulate positive social attitudes towards people with bodily impairments and more positive attitudes should encourage more positive physical planning.

### **7.2.2 Perceptions of, and attitudes towards, disabled people**

The negative attitudes of employers and co-workers based on prejudice, misinformation and/or lack of knowledge about specific disabilities present another barrier to overcome. People often fail to recognise the abilities of people with disabilities (Croxen, 1984; Imrie, 1996b; International Labour Office, 1984; Roulstone, 1998a; Barnes et al, 1998). It is also important to recognise that ability is not fixed and there is always potential for achievement (Morris, 1989). The idea that a physical disability simultaneously renders a person



intellectually disabled is one of the most common misconceptions (Seymour, 1998; Roulstone, 1998a; Johns, 1991). People in wheelchairs are often treated as though they have other types of impairments such as hearing impairments and not just SCI. They may be shouted at or totally omitted from conversation (for example, "Does he take sugar?") (Morris, 1989). One person in this study said;

"People think you are mental because you are in a chair ... they don't understand...  
I don't want people's sympathy, just their understanding."

Morris (1989) suggests that people with SCI get on with life in the best possible way and do not want to be thought of as "brave heroes" and do not like being talked about as "wonderful" or "marvellous". According to the Disability Sector Vocational Coalition (1997), disabled people do not want preferential treatment, but do want a level playing field for entry into the labour market. It suggests that people with disabilities want work that utilises their skills, provides job satisfaction, appropriately remunerates them and offers the same kind of protections (such as a safe work environment) and benefits (for example, holiday pay and training) as non-disabled people. It also suggests that disabled people want their abilities to be recognised through appropriate career advancement opportunities. In other words they want the same things out of work that non-disabled people do.

Employers are often reluctant to employ people with disabilities because they associate disability with extra cost. They often assume poor performance will rise dramatically when disabled people are employed, and, that needs for special equipment and/or workplace modifications will add to output costs. Many employers presume a disabled worker is likely to be less productive than an able-bodied worker in the same job and often believe that disabled workers have higher absenteeism and accident rates (see, for example, International Labour Office, 1984; Barnes et al, 1998; Topliss, 1982; Johns, 1991; Underwood & Utatao, 1998; Imrie, 1996b). However, this is not the case as research has shown that people with

disabilities provide extra stability and motivation to the workplace, are reliable and loyal workers, and bring an extra dimension to the attitudes and productivity of those around them (see, for example, Workbridge, 1996b; Bascand, 1987; Underwood & Utatao, 1998). According to Kettle and Massie (1986), the available evidence indicates that people with SCI have lower rates of absenteeism and accidents than the general population.

Chapter Two illustrated that the acceptance of various disabilities has changed over time and often depends on the type of disability and the context in which they are encountered. There have been studies conducted on employer attitudes towards people with disabilities. For example, a New Zealand study by Studholme (1994) surveyed 186 Christchurch employers' perspectives on hiring people with disabilities. This study illustrated that the attitudes towards people with disabilities varied according to the type of disability and whether or not the employer had had experience of employing such people. In general, it found that employers with experience of people with disabilities were more receptive to employing them and were more prepared to spend more money knowing that the costs of accommodation would be offset by the benefits gained as a consequence. It also showed that people with physical disabilities were more likely to be employed than people with sensory, neurological, cognitive, developmental or behavioural disabilities. Studholme (1994) acknowledged that there was a trend for people with more obvious disabilities to be employed in positions that required less contact with customers, clients and the public. This was usually because employers did not want to lose business opportunities by employing a person who was "less visually appealing". Studholme (1994: 164) concluded that:

The apparent lack of acceptance of people with visible disabilities represents a major employment barrier to people with disabilities. Despite having the necessary skills and ability, their career paths may be thwarted by an employer who is unable to see beyond the person's disability.

In a survey of employers attitudes towards employing people with disabilities in the Wellington area, Bascand (1987) found that the larger the firm the greater the likelihood it would be employing disabled people. The survey showed that the manufacturing and service industries were more likely to employ visibly disabled workers while the financial and sales sector appeared less likely. Only thirteen of the eighty nine employers surveyed felt that they could accommodate a person with a disability in their work environment. The most frequently excluded disabilities in ranking order were blindness, followed by people in wheelchairs, mental illness and hearing impairments (Bascand, 1987).

Dench et al (1996) examined the recruitment and retention of people with disabilities in a national survey of 1250 employers in Britain. They found that the nature of the work emerged as the most commonly perceived barrier to employment of people with disabilities. Difficulties adapting workplaces due to the existence of too many stairs, lack of lifts, poor access and dangerous machinery were frequently mentioned. Being unable to move around the workplace, necessity for physical strength, and safety concerns were also mentioned. People with sight impairments, mental handicaps and/or learning difficulties were reported to be the most difficult to employ. Those with difficulties affecting mobility came lower down the list in terms of perceived difficulty to employ. The majority of the respondents were prepared to pay more to accommodate an existing employee, who had become disabled during the course of their employment, rather than for a new recruit who was already disabled (Dench et al, 1996). Clearly, employers who have had previous contact with disabled people tend to be more accepting. This illustrates the importance of familiarity for dispelling misconceptions and encouraging awareness of the capabilities of people with disabilities (Dear et al, 1997). Johns (1991) suggests that expectations of the employability of people with disabilities are bound to rise because of the integration of children with disabilities into mainstream schools.

The first major challenge to employment for people with disabilities is at the recruitment and selection stage. Greater choice of applicants for declining numbers of jobs has enabled employers to be highly selective in their recruitment practices. If people do not disclose that they have a disability when they apply for a job they are more likely to get an interview. Employers have been found to be more likely to turn down a person with a disability for a job even when their qualifications are the same as a non-disabled person (see, for example, Barnes et al, 1998; Ravaud et al, 1992). Workbridge advise people not to tell to potential employers that they have a disability until they get an interview. Studholme (1994) found that employers wanted information on individuals' medical history. This seems to reflect the notion that people with disabilities are ill and consequently not fit for work. In New Zealand, the Human Rights Act 1993 prevents employers from discriminating against employees and potential employees on any grounds (including disability or perceived disability). However, employers may seek information about a disability, or previous gradual process injuries (such as back problems, repetitive strain injuries or occupational overuse syndrome), if the purpose is to prevent aggravation of a pre-existing condition or to accommodate the effects of the injury or illness within the work place (Department of Labour, 1999).

### **7.2.3 Barriers to education**

Historically, there have always been a variety of barriers to education and training for people with disabilities including the issue of physical accessibility. Other barriers to participating in tertiary sector education are affordability with respect of the extra costs of disability that can fall on student with disabilities such as additional transport costs (Disability Sector Vocational Coalition, 1997). Gray and Neale (1991) found that disability and age were the main reasons for people with disabilities not wanting to undertake further education or training. Other limiting factors were the cost and location of courses. Welham (1997)

acknowledges that voice recognition software, the increasing use of the internet, e-mail and other forms of electronic data transfer, and a constantly expanding range of assistive devices, are enabling increasing numbers of people with disabilities to retrain and enter the labour market. Distance learning, using various technologies, is another means of educating disabled people. This gives people with disabilities access to educational resources and institutions from within a familiar and accessible environment, and they are responsible for their own learning at the pace and time that suits them (Welham, 1997). The study by Chou et al (1996) illustrates the potential of distance learning techniques for students with severe spinal cord injuries.

### **7.3 The barriers or difficulties encountered by people with SCI when trying to find employment after injury**

This study has examined the barriers to employment from the perspective of people with SCI. The seventy people interviewed were asked what sort of difficulties or barriers they had encountered when trying to find work following SCI (Table 7.1). Over half of the respondents (51.4%) had not looked for work since their injury, although it is important to recognise that many of these individuals (38.9%) had been injured for less than two years and were often still adjusting to their disability. The issue of accessibility was the leading barrier or difficulty identified by the participants (18.6%) followed by employer attitudes and perceptions (17.1%). Several people said that when they had returned to work they had to re-prove their abilities. The respondents who were working at the time of interview seem to have encountered more barriers or difficulties in finding employment compared to those who were not working (Table 7.1). This is not surprising considering the majority of the individuals who were not employed (76.6%) had not looked for work since sustaining their SCI.

**Table 7.1 The barriers or difficulties that the people with SCI have encountered when trying to find work after their injury**

Barriers or difficulties	Working (n)	Not Working (n)	Total (n)
Accessibility issues	10	3	13
Employer attitudes and perceptions	7	5	12
None	7	4	11
Time you can start / Getting to work by 9am	2	1	3
Transportation difficulties	2	1	3
Having enough attendant support hours	1		1
Lack of contacts		1	1
Not initially motivated for finding work	1		1
Temperature of the workplace		1	1
Bowel and bladder control issues		1	1
<b>Total*</b>	<b>30</b>	<b>17</b>	<b>47</b>

\* There were 47 responses from 34 participants (23 working and 11 not working) and 36 people had not looked for work since their injury and therefore had not encountered any barriers or difficulties finding work

(Source: Access to employment opportunities for people with SCI Survey)

### **7.3.1 The barriers or difficulties encountered by people with SCI who were employed at the time of interview**

**Table 7.2 Modifications to current workplace to improve accessibility**

Modifications	Frequency (n)
No modifications required	13
Ramps	4
Wheelchair accessible toilet facilities	3
Swinging gates (so I could open & close the gates on the farm)	1
Self-opening door was installed	1
Relocated the till & made a new workshop bench	1
Office area was built onto my house so I could work from home	1
Non-slip floor was put into the shop	1
<b>Total*</b>	<b>25</b>

\* There were 25 responses from 23 participants

(Source: Access to employment opportunities for people with SCI Survey)

The individuals who were working at the time of interview were asked if their workplace had required any modifications to improve accessibility (Table 7.2). The majority of workplaces

did not require any modifications (52%). This could indicate that perceptions of inaccessibility are greater than actual inaccessibility or that people choose jobs due to good access or that employers who did not need to modify their workplaces are more willing to employ people with disabilities. Four workplaces required ramps and three needed wheelchair accessible toilet facilities.

**Table 7.3 Special equipment to enable participants to do their jobs**

Special Equipment	Frequency (n)
No special equipment required	17
Computers	2
Lower tables so everything is at the right height	1
Special wheelchair	1
Vehicle and radio gear for the farm	1
Over Head Projector for teaching	1
Total	23

(Source: Access to employment opportunities for people with SCI Survey)

The participants who were employed were also asked if their workplace needed any special equipment for them to do their job (Table 7.3). Of these people 73.9% did not require any special equipment to enable them to do their job.

### **7.3.2 The barriers or difficulties encountered by people with SCI who were not working at the time of interview**

The individuals who were not employed at the time of interview were asked what their main reasons for not working were (Table 7.4). Over one third of the respondents (38.3 %) cited their injury or health as their main reason for not working. The fourteen participants who had been injured for less than two years all said that they were not yet physically able to work and had not completed their rehabilitation. Not only do people with disabilities face constraints to employment that originate in the workplace, but they may also face

*intrapersonal constraints*, that limit or prohibit employment, which originate from within the person (Buchanan & Raymore, 1997). Buchanan and Raymore (1997: 23) suggest that:

The perceptions that an individual with a disability has about the attitudes of significant others, their abilities, level of confidence, manageability, enjoyment, and stress may impact on the employment opportunities in which they become involved.

**Table 7.4 Participants' main reasons for not working**

Reasons for not working	Frequency (n)
Because of injury / Health / Medical complications	18
Not yet physically able to work yet / Have not finished rehabilitation yet	14
Currently studying	3
Lack of qualifications	3
Don't want to work / Too lazy / Lack of motivation	3
Because of pain	3
Because it is hard to find a job	3
Not knowing what I'm capable of doing	3
Not confident enough to work	1
Because of my baby	1
Because Workbridge has not organised another placement yet	1
Unnecessary pressure	1
Retired	1
No incentive for me to work	1
<b>Total*</b>	<b>56</b>

\* There was a total of 56 responses from 47 participants who were not working at the time of interview. (Source: Access to employment opportunities for people with SCI Survey)

The ideas for work and areas of interest for people who sustain SCI tend to remain similar to their pre-injury interests (Crisp, 1990; Kanellos, 1985). One factor that appears to make it difficult for people with SCI to gain employment is their, and the general public's, thinking of what jobs have been or are being done by people with SCI, rather than what individuals with SCI would like to do (Decker & Schulz, 1985; Thompson, 1997). The individuals in this study who had sustained their SCI when they were young (that is less than 25 years of age) and had limited educational qualifications and/or limited work experience seemed to find it difficult to decide what they would like to do. Those injured later on in life, who could not return to their previous occupation because of their SCI, also appeared to find it difficult to



identify exactly what sort of work they would like to do or would be capable of doing. Many people seem to have firm ideas about what an employer will and will not accept at work

Gray and Neale's (1991) *Survey of Employment and Training Experiences of People with Disabilities* found that disability was seen as the main barrier to finding employment. Lack of jobs was also considered an important barrier along with employers' attitudes and age. A study by the Hillary Commission and Workbridge (1994) examined the attitudes of 1021 people with disabilities towards employment. It too found that most respondents cited disability as their first barrier to getting employment. They said their disability either limited their chances of getting employment or prevented them from getting a job altogether. However, many of the individuals did recognise that they lacked the necessary skills and qualifications.

**Table 7.5 What do people see standing in the way of them getting a job at the moment?**

Barriers or difficulties	Frequency (n)
Lack of qualifications / Experience	9
Health / Injury	9
Physical Strength / Still recovering	7
Pain	4
Economic climate / Very few jobs out there (especially for people in wheelchairs)	4
Myself / Lack of motivation	4
Not an issue / Choose not to work	3
Time	3
Nothing	2
Transportation	1
Operations	1
Lack of contacts	1
Somebody not employing me	1
Need an employer that understands	1
My baby	1
Problems with bladder and bowel	1
Total*	51

\* There were 51 responses from 45 participants.

(Source: Access to employment opportunities for people with SCI Survey)

The participants in this study who were not working were also asked what they thought was standing in the way of them getting a job (Table 7.5). Lack of qualifications and experience, and injury or health were the most frequently mentioned barriers standing in the way of respondents finding employment. Interestingly, nobody mentioned age as being a barrier even though six people were over fifty years of age at the time of interview and were not working.

## 7.4 Enabling Technology

According to Workbridge (1996b: 6), "medical and technological advances are presenting new opportunities for those who have considerable barriers to placement into employment". Welham (1997) suggests that technological advances in computing and telecommunications are having a profound impact in reducing the "physical" barriers confronting people with disabilities. These advances are making some occupations increasingly accessible to people with disabilities, enabling them to use their abilities more fully and exert greater control over their own futures (Welham, 1997; Johns, 1991; Roulstone, 1998a). *Enabling technology* is a term which has been applied to new developments which enables people with some types of disability, even if "severe", to become "technologically equal" to their non-disabled peers (Johns, 1991). For example, problems of limited movement can be alleviated with voice recognition computer software (Johns, 1991; Asher, 1999). In a computer based environment a person's disability does not have to be known to other users (Welham, 1997; Roulstone, 1998a).

Roulstone (1998a) in his study *Enabling Technology* surveyed seventy eight disabled workers using new technology and conducted thirty in-depth semi-structured interviews. A third of the people interviewed by Roulstone (1998a) felt that the pace of change was too much for them. In particular, women felt threatened and insecure because of inadequate

training and use of technology. A small number of people found that they came under pressure to increase output when new technology was introduced and were prevented from taking the necessary breaks. On the other hand, the same survey found that people with severe and visible impairments reported benefits from communicating via word processing and email which helped to improve their abilities that co-workers otherwise underestimated.

There are also barriers to accessing enabling technology. Roulstone (1998b: 115) suggests that despite the potential benefits of new technology:

Access to and use of new technology, as with access to work and society generally, may be shaped by pre-existing disabling forces. A failure to obtain or keep work, then, is due to the attitudinal and physical barriers faced by disabled people ...

Barnes et al (1998: 15) also suggest that "[e]ven in the area of new technology, some of the greatest barriers to employment opportunities for disabled people are created by the attitudes of other people". The high cost of enabling technology remains a problem (International Labour Office, 1984). According to Welham (1997), the greatest barrier to accessing information technology for people with disabilities is the initial cost of getting necessary equipment and the continuing cost of accessing certain services such as the Internet. Although the Internet makes employment and learning more accessible to people with disabilities the technologies may isolate them to teleworking modes (Welham, 1997).

Over half of the people in the current study (54.2%) said that they had access to the Internet. However, the majority of the participants (60%) perceived their computer skills to be non-existent or very limited. Only 17.1% considered their computer skills to be good or excellent and the rest (22.9%) thought their computer skills were average.

## 7.5 New ways of working

Roulstone (1998b) recognises that the growth of white collar, computer based working owing to the technological shift away from manual work has also allowed access to new working environments for disabled people. The main area where SCI may cause difficulty with regard to employment concerns ADL, such as getting up and getting dressed which take longer (Kettle and Massie, 1986). It can therefore, be difficult for a person with SCI to start work early in the morning. Berthoud et al (1993) suggest that there are many ways that a willing and informed employer can support the participation of people with disabilities in the workplace.

For some people with disabilities working from home or setting up a small business from home may be a viable option. Working at home avoids travel difficulties and enables people to be in a physical environment that is more suited to their specific disability and needs (such as wheelchair accessible toilets and shelving at an accessible height) (Employment and Skills Formation Council, 1994; Welham, 1997; Johns, 1991; Occupational Health and Safety, 1981; Barnes et al, 1998). *Teleworking* (also known as telecommuting and distance working) involves working from a separate location to an employer. It often requires combining information and communication technologies to keep the employee and employer in regular contact. Teleworking helps to overcome the fundamental problem of actually getting to and around the workplace for many people with disabilities. Another important benefit of teleworking is the flexibility of hours, which is particularly important for those who tire quickly and require regular breaks. It can be difficult to accommodate these needs and retain productivity when people are restricted to traditional working hours (Welham, 1997; Johns, 1991). However, Barnes et al (1998: 16) suggest that:

Some employers are resistant to the idea, being prepared to countenance it only in cases where the employees involved are highly skilled, highly paid and therefore in a

strong bargaining position. Because of the under-representation of disabled people in professional occupations, their access to teleworking has been particularly limited.

*Self-employment* also offers flexibility and allows individuals to control their work situation to suit their needs. It has advantages to those individuals who would find working a regular five-day week or even a regular part-time job daunting (Johns, 1991; Gray and Neale, 1991). Three individuals in this study were self-employed and seven (30.4%) worked from home.

However, some people do not live in appropriate housing for commercial activity and/or may not have the space to work from home. The issue of social contact still remains and working from home does not increase the visibility of people with disabilities (Johns, 1991). The Employment and Skills Formation Council (1994) also suggests that people with disabilities often have a lower financial base to start a small business and as a consequence banks are more reluctant to provide loans.

## 7.6 Chapter Summary

This chapter has highlighted some of the difficulties and barriers that people with SCI face when seeking employment after their injury. People with disabilities experience greater barriers to gaining and maintaining employment due to of a variety of factors including the obvious physical limitations of the workplace environment along with work practices, the negative attitudes of employers and co-workers, and intrapersonal constraints. Although new ways of working and technological advances are reducing the 'physical' barriers facing people with disabilities, negative attitudes continue to act as a major barrier to accessing employment opportunities for disabled people.

The following chapter will look at the importance and benefits of working and also the effects of unemployment. Some of the life changes after SCI will also be examined.

## **CHAPTER EIGHT: Life Changes After SCI**

### **8.1 Introduction**

It has been shown that a variety of factors and barriers affect return to work after SCI. Work is highly valued in our culture and it is often regarded as one of the most important social roles that many people perform (Berkowitz & Hill, 1986). This chapter investigates both the importance of work and the effects of unemployment. Some of the life changes following SCI and outcomes of working or not working on people's perceived health status, social outcomes and life satisfaction will also be examined.

### **8.2 The Importance of Work**

Work is considered important for a variety of reasons and it serves many functions. It provides financial security, challenges, social interaction and is a means of increasing self-esteem (Smith, 1997; Young et al, 1994; Shirley et al, 1990). Berthoud et al (1993) suggest that employment is central to social and psychological well-being as it provides opportunities for social contact, personal development, and the accumulation and use of skills. The National Health Committee (1998: 8) also suggests that:

Employment enhances social status and improves self-esteem, provides social contact and a way of participating in community life, and enhancing opportunities for regular activity, which all help to enhance individual health and well-being.

It is also important to recognise that even though employment is important for good health, certain occupations (for example, forestry, construction work and mining) carry risks to health such as injury or even death (National Health Committee, 1998). According to the Disability Sector Vocational Coalition (1997):

Being employed is an important aspect of belonging to a community. A sense of identity is derived from work, and a feeling of contributing to society. Work may involve participation in daily activities, work experience, or employment. Income generated from work enables a person to have a greater level of economic

independence, which in turn opens up other opportunities to make choices that enhance quality of life.

In contrast unemployment may lead to a reduction in income, loss of social status and self-confidence (Shirley et al, 1990). Young et al (1994: 229) suggest that because "work is highly valued in our culture, those who do not work are often perceived as not fully participating in society". People who are unemployed for long periods of time may feel isolated and devalued. Berthoud et al (1993) suggest that these feelings may be even more severe for disabled people, who often face additional isolation because of environmental constraints, inadequate support and additional devaluation as a result of negative social attitudes towards impairment. Lonsdale (1990: 98) suggests that:

Aside from generating an income, employment also structures the day and provides interests, friendships and gives a certain pace to life. The loss of a job and the consequent unemployment, or the inability to take on paid work due to disability, can therefore mean not only material hardship but also loneliness, boredom, loss of confidence, and the problem of having surplus unstructured time.

Although productive activities (such as being a student or a homemaker) are recognised as being beneficial, the importance attached to paid employment in assisting adjustment to SCI continues to be the subject of strong consensus among rehabilitation professionals and spinal cord injured people themselves (Ville & Ravaud, 1996; Kanellos, 1985). Disabled people who return to employment often benefit in a number of ways. People with SCI who work report fewer health problems, increased subjective well-being, and are generally more satisfied with their social lives than those not employed (Krause, 1992). Decker and Schulz (1985) also found a significant positive relationship between being employed and life satisfaction. Similarly, the employed respondents in Crisp's (1992) study had more positive self-perceptions than the unemployed respondents. He suggested that people with SCI who are employed are more likely to have better financial resources and are therefore, more likely to be mobile and involved in satisfying social activities than those who are unemployed.

The twenty three participants who were in paid employment at the time of interview were asked whether their current job gave them a sense of satisfaction and achievement (Table 8.1). The vast majority of the individuals (78.3%) said that they got a tremendous amount of satisfaction and sense of achievement from working. For example, one person said, "work gives me something to focus on ... it is good to get out and see people".

**Table 8.1 Job Satisfaction**

Sense of satisfaction and achievement from current job	Frequency (n)	Percent (%)
Yes - definitely / certainly / I love it / very much so	18	78.3
Yes & No	3	13.0
No	2	8.7
Total	23	100

(Source: Access to employment opportunities for people with SCI Survey)

The people who were employed at the time of interview were also asked whether their current job required them to use all of their skills and abilities (Table 8.2). The majority said yes (69.6 %) however, several respondents said that their SCI meant they could not use all of their skills and abilities because they were not able to do physical work. Two people commented that their jobs were allowing them to develop new skills.

**Table 8.2 Utilisation of skills and abilities in current job**

Utilisation of all of your skills and abilities in current job	Frequency (n)	Percent (%)
Yes - most of them	16	69.6
No	5	21.7
Yes - definitely & allows me to develop new skills which I do not have	2	8.7
Total	23	100

(Source: Access to employment opportunities for people with SCI Survey)

People were asked if they would like to work more hours (Table 8.3). But the majority of the participants (60.9%) replied in the negative. This was usually because people thought they



were already working as many as they were physically capable. One person commented that he did not want to work any more hours, as his health was deteriorating and financially he did not need to. Some respondents had recently started back at work and hoped to increase their hours in the future. Participants worked between 3-55 hours per week (for example, one person was only working three hours per week because he had just started back at work and was hoping to increase his work time in the future).

**Table 8.3 Work more hours**

Would you like to work more hours?	Frequency (n)	Percent (%)
No	14	60.9
Yes	6	26.1
Sometimes I do	2	8.7
Yes & No	1	4.3
Total	23	100

(Source: Access to employment opportunities for people with SCI Survey)

The employed individuals were also asked how they felt about their career advancement and promotional prospects (Table 8.4). Many people (43.5%) said that they were happy in their current job and that they either had no desire for promotion or it was not an issue for them. Some respondents (34.8%) felt that their career advancement and promotional prospects were fairly promising. In contrast, four individuals thought their prospects were limited because they could not work very many hours.

**Table 8.4 Career advancement and promotional prospects**

Feelings about career advancement and promotional prospects	Frequency (n)	Percent (%)
Not an issue / No desire for promotion	10	43.5
Pretty good - lots of further involvement possible	8	34.8
Poor / Very limited	4	17.4
I am currently looking for something better	1	4.3
Total	23	100

(Source: Access to employment opportunities for people with SCI Survey)

### 8.3 The Effects of Unemployment

Unemployment has been generally linked to a number of negative psychological effects such as high levels of stress, anxiety, despair, depression, loss of self-esteem and self-confidence (see, for example, Pernice, 1998; Rodriguez et al, 1997; Shirley et al, 1990; National Health Committee, 1998). Despite the general negative effects of not working, it has been recognised that the experience of unemployment varies considerably depending on people's age, gender, marital status, income, social support, reason for job loss, satisfaction with previous work, commitment to employment, length of unemployment and work attitudes (Pernice, 1998; Ezzy, 1993). The greater the employment commitment of an individual the stronger the negative effects of unemployment are on mental health and self-esteem (Ezzy, 1993). Unemployment has been found to have a more direct impact on men because their range of social roles is limited and therefore, employment is more central to their identity than it is for women, whose social roles are generally more diverse (Barnett et al, 1995). Shirley et al (1990) suggest that the neglect of research into women's unemployment may reflect the popular view that women can revert to a traditional homemaking role. The Society for Research on Women (1994) investigated *The Effects of Unemployment on Women* in Christchurch. It found that loneliness, boredom, a deterioration in social life, and depression were common responses to job loss. Shirley et al (1990) recognise that unemployment is also associated with a wide range of social problems such as premature death, suicide, marital breakdown, child abuse, racial conflict, violence and crime, increased alcohol consumption and the illegal use of drugs. They also acknowledge that parental unemployment has been associated with deterioration in children's health, behaviour and educational attainment and also adversely impacts on children's aspirations.

Attitudes towards work moderate the negative effects of unemployment. These are dependent on the extent to which a person wants a paid job. People generally become discouraged when they cannot find a job. Individuals can develop a fatalistic attitude whereby they accept that no matter how hard they try to find work, they will never find work and as a consequence they exclude themselves from the labour market (Pernice, 1998). Employment in itself will not necessarily produce a positive outcome because of the adverse effects of unsatisfactory work. Therefore, people who find satisfactory work experience enhanced well-being and those who take on poor jobs or become unemployed experience a deterioration in well-being (Graetz, 1993). Some people who become unemployed may experience an improved psychological well-being if they leave an unsatisfactory job (Ezzy, 1993). According to Barnett et al (1995: 139) an unsatisfactory job may not always be better than no job at all and "that work is only beneficial if it is safe, secure, satisfying and properly remunerated". Shirley et (1990: 11) recognise that "work can be repetitive, monotonous and boring" and it can lead "to a loss of autonomy as well as feelings of inadequacy and incompetency".

Pernice's study (1998) investigated employment attitudes and their relationship to the mental health of 137 unemployed people with disabilities who were either on an unemployment benefit (n=110), an invalid's benefit (n=8) or receiving ACC (n=19). The results indicated that those receiving ACC had the most negative attitudes towards work and were the most financially advantaged group. Thirty one percent of those receiving ACC were interested in receiving training compared with only two percent of the people on the unemployment benefit and nobody on the invalid's benefit. Pernice (1998) suggests that their concerns about the future of ACC seemed to increase their motivation to train in the hope of getting a better job. Although people receiving ACC are expected to be actively looking for work only a small minority were interested in paid work (16%) and 37% reported that they had worked out satisfactory alternatives to formal employment for example, voluntary work, being busy

and active with their interests and hobbies, and occasional cash jobs. Although all groups had poor mental health, the people on ACC had the highest levels of distress which seemed to be due to concerns about their financial security in the future (Pernice, 1998).

A study by the Hillary Commission and Workbridge (1994) examined the attitudes of 1021 people with disabilities towards employment. It found that those who were employed seem to value the importance of working more than those who did not have a job as they found it harder to see the benefits of being employed. Work was considered to be important for the income possibilities, self-esteem and confidence, independence, social contacts and it also gave people something to do.

The forty seven people in the current study who were not in paid employment when interviewed were asked about what they thought were the worst aspects of not working (Table 8.5). Missing the social contacts that work provides was most frequently mentioned (47.7%), followed by boredom and difficulties of filling in time (27.7%), and financial difficulties (17.0%). Interestingly, ten participants (21.3%) said that there was nothing bad about not working. These individuals indicated that they had never really liked working and that they only worked to pay the bills. For example, one person said;

"Nobody works because they want to... people only work because they have to for the money".

This suggests that these people may have been working in unsatisfying jobs when they were injured. Consequently, these individuals often said they would only return to work if they found a job that they really wanted to do. Some other comments that people made regarding the negative aspects of not working included;

"You get lazier and lazier when you're not working"

"I miss not being able to do the physical stuff and having to rely on people to do stuff...from being totally independent to being dependent on people"

"It's financially difficult trying to bring two up two kids... I miss the social side of work... empty wasted days"

"Being on ACC is not very satisfying especially when you know you are capable of working"

**Table 8.5 The bad things about not working**

Bad things about not working	Frequency (n)	Percent of sample (%)
Miss the social contact	21	44.7
Boredom / Hard to fill in time & keep the mind occupied	13	27.7
Nothing	10	21.3
Financial difficulties / Not getting paid / Miss the money	8	17.0
Lack of independence / Relying on others	4	8.5
Miss the challenge and joy of succeeding	3	6.4
Miss not being able to do the physical stuff	3	6.4
Not being able to participate	2	4.3
Being on ACC	1	2.1
The effect it has on my children's esteem	1	2.1
Total*	66	

\* There were 66 responses from 47 participants.

(Source: Access to employment opportunities for people with SCI Survey)

The people who were not employed at the time of interview were also asked what the good things about not working were (Table 8.6). The majority of respondents (42.6%) felt that there was nothing positive about not working. These people made comments such as:

"No [there is nothing good about not working]... that's why I took up smoking... I just sit around all day and do nothing... I don't like being a nuisance"

"Not really [anything good about not working]... because I am just sitting around doing nothing"

Many people (29.8%) did however indicate that one of the good aspects about not working is having more freedom and time to do what they want to do. Some people (12.8%) cited being able to spend more time with their children as one of the good things about not working. For example, one person said it was good having "more time for the family whereas before my injury I was too busy working".

**Table 8.6 The good things about not working**

Good things about not working	Frequency (n)	Percent of sample (%)
Nothing	20	42.6
More freedom and time to yourself	14	29.8
Being able to spend more time with my family	6	12.8
Don't have to get up early	5	10.6
Less stress	4	8.5
I'm still doing something worthwhile & productive	2	4.3
Watching more sport	1	2.1
Not having to do night duty and having public holidays off	1	2.1
<b>Total*</b>	<b>53</b>	

\* There were 53 responses from 47 participants.

(Source: Access to employment opportunities for people with SCI Survey)

## 8.4 Life after SCI

According to Smith (1999), better rehabilitated persons with SCI led more rewarding lives, require less care and are more likely to be actively employed than those who are less well rehabilitated. Berkowitz (1994: 20) indicates that:

...as a consequence of SCI, less time was generally spent working, attending school, and socializing with friends and more time was spent engaging in activities related personal care.

Many participants talked a lot about what they did before their injury and how their life had subsequently changed since their injury (Table 8.7). Most people (60%) said that they still had the same number of friends when interviewed compared to when they were injured, although people often commented that you do find out who your true friends are. Some respondents (34.3%) felt that they had less contact with other people which was mainly due to the fact that they were not working. The majority of people (54.3%) said that they made less social outings since their injury mainly because of accessibility problems. There was also a significant reduction in the sports participation (62.9%) and leisure activities (47.1%) of the individuals in this study post injury because of the physical limitations of SCI and/or access

issues. Many people commented that going away on holiday was more expensive and required a lot more planning because of their SCI. Nevertheless, some people said that they now go away on holiday more often (31.4%) compared with before their injury.

**Table 8.7 Life now compared with before injury**

Life at interview	More		About the Same		Less	
	n	%	n	%	n	%
Number of Friends	11	15.7	42	60.0	17	24.8
Contact With Other People	20	28.6	26	37.1	24	34.3
Social Outings	8	11.4	24	34.3	38	54.3
Sports Participation	7	10.0	19	27.1	44	62.9
Leisure Activities	14	20.0	23	32.9	33	47.1
Holidays	22	31.4	22	31.4	26	37.1

(Source: Access to employment opportunities for people with SCI Survey)

Many people who sustain spinal cord injuries do go on to lead enjoyable, satisfying and rewarding lives regardless of age when injured and level of injury (see, for example, Kennedy et al, 1995a; Cushman & Hassett, 1992; Decker & Schulz, 1985). Crisp (1992: 422) suggests that:

While persons with SCI do have special needs and deal with problems not faced by non-disabled persons, they are not necessarily burdened by psychologically by their disability.

People in this study were asked which words best described how they felt about their lives at the time of interview (Table 8.8). The choices given included: happy, satisfied, not coping well, depressed, unhappy, up and down, mostly OK and frustrated. Over half of the individuals (52.2%) who were working said they were happy compared with 38.3% of those who were not working. A higher percentage of the working respondents (39.1%) said they were satisfied with their lives compared with 21.3% of those who were not working. People

often said that they felt frustrated (25.7%) because of the daily frustration associated with the ongoing physical difficulties resulting from SCI or the problems they were having with ACC. Five of the people who were not working (10.6%) said that they were depressed, three (6.4%) did not think that they were coping and two (4.3%) felt unhappy. In contrast, the people who were working who did not experience any of these feelings.

**Table 8.8 Participants' feeling about their life at the time of interview**

Feelings about their life	Not Working		Working		Frequency	
	n	%	n	%	n	Percent*
Happy	18	38.3	12	52.2	30	42.9
Mostly OK	12	25.5	10	43.5	22	31.4
Frustrated	12	29.8	6	26.1	20	28.6
Up and down	15	31.9	4	17.4	19	27.1
Satisfied	10	21.3	9	39.1	19	27.1
Depressed	5	10.6	0	0.0	5	7.4
Not coping well	3	6.4	0	0.0	3	4.3
Unhappy	2	4.3	0	0.0	2	2.9
Total**	79		41		120	

\* Percent of the participants

\*\* There were 120 responses from 70 participants (47 not working and 23 working).

(Source: Access to employment opportunities for people with SCI Survey)

### 8.4.1 Marital Status

Spinal cord injuries can put a lot of strain on family life and relationships. The available evidence suggests that those who have an established partner at the time of injury do not have a greater separation or divorce rate than the general population (see, for example, Smith, 1999; Hoad et al, 1990; Gidlow, 1977). Hoad et al (1990: 97) suggest that “most of those who did not get on prior to the injury, continued not to”. According to Gidlow (1977), some couples' marriages may have been having difficulties before the SCI and this may be the catalyst rather than the cause of separation, or it may simply reflect the increasing trend of separation in wider society. The life changing effects of SCI not only have an impact on



sexual function but also broader sexuality issues, such as self perception of attractiveness and a heightened consciousness of bodily image, that may impact on relationships and self-concept. Those who do not have an established partner at the time of injury sometimes appear to struggle with initiating relationships (Smith, 1999; Kennedy et al, 1995a).

More participants in this study were single at the time of injury compared to at the time of interview (47.1% versus 32.9%) (Table 8.9). This is not surprising considering that young people often sustain spinal cord injuries. Similar numbers of individuals were married at the time of injury and at the time of interview. However, more people were in de-facto relationships (17.1%) when interviewed compared to when injured (8.6%). Forty participants had partners when they were interviewed and thirty two of the partners were employed (twenty two full-time and ten part-time). Four respondents had separated or divorced since their SCI and one individual had remarried.

**Table 8.9 Marital status before injury and at the time of interview**

Marital Status	Before Injury		At Interview	
	n	%	n	%
Single	33	47.1	23	32.9
Married	28	40.0	27	38.6
De-facto	6	8.6	12	17.1
Separated or Divorced	3	4.3	7	10.0
Remarried	0	0.0	1	1.4
Total	70	100	70	100

(Source: Access to employment opportunities for people with SCI Survey)

## **8.6.2 Household Situation**

Many people rely on family members for assistance with daily living and personal care. Seymour (1998) suggests that parental help may be resented because it is seen to perpetuate the dependencies of childhood. Dependence increases people's vulnerability to changes in

circumstances, for example, if a partner leaves, becomes ill or dies (Morris, 1989). Cushman and Hassett (1992) found that people with SCI who were in a preferred living situation had a significantly better perceived quality of life.

At the time of this study the majority of the participants (57.1%) were living with either their partner or partner and child(ren), followed by 18.6% who were living alone (Table 8.10). One person who had been working full-time prior to his SCI said that; "One of the strangest things was having to be at home with my wife 24 hours a day". Nine individuals were living with their parent(s). Four of these individuals commented that they had found it difficult returning to live with their parents after SCI because they were used to being very independent before their injury and found it difficult being dependent again.

**Table 8.10 Participants' Household Situation**

Household Situation	Frequency (n)	Percent (%)
Living with partner	21	30.0
Living with partner and child(ren)	19	27.1
Living alone	13	18.6
Living with parent(s)	9	12.9
Living with flatmates	6	8.6
Other*	2	2.8
Total	70	100

\* The 'Other' category included one person who was living with his sister & brother in-law and one person was living with her children & no partner.

(Source: Access to employment opportunities for people with SCI Survey)

### 8.6.3 Income

According to the National Health Committee (1998: 8),

Income is the single most important modifiable determinant of health and is strongly related to health and well-being... The link between poverty and ill health is clear; with few exceptions, the financially worse off experience the highest rates of illness and premature death.

In New Zealand disabled people have significantly lower incomes than their able-bodied counterparts. Fifty four percent of people with disabilities who are working receive a gross personal annual income of less than \$15,000 compared to 42% for those without disabilities. Disabled women have the lower incomes of all. Only 8% earn \$30,000 or more compared to 22% of disabled men (Statistics New Zealand, 1998).

**Table 8.11 Participants' income at interview**

Income	Not Working		Working		Total	
	n	%	n	%	n	%
Under \$10,000	6	12.8	1	4.3	7	10.0
\$10,001-\$15,000	7	14.9	1	4.3	8	11.4
\$15,001-\$20,000	7	14.9	2	8.7	9	12.9
\$20,001-\$25,000	2	4.3	2	8.7	4	5.7
\$25,001-\$30,000	5	10.6	5	21.7	10	14.3
\$30,001-\$40,000	5	10.6	5	21.7	10	14.3
\$40,001-\$50,000	1	2.1	2	8.7	3	4.3
Over \$50,001	4	8.5	2	8.7	6	8.6
Don't Know	8	17.0	3	13.0	11	15.7
Refused	2	4.3	0	0.0	2	2.9
Total*	47	100	23	100	70	100

(Source: Access to employment opportunities for people with SCI Survey)

In this study the majority of people (54.3%) were earning \$30,000 or less and 34.3% were earning \$20,000 or less (Table 8.11). A surprisingly high percentage (15.7%) of the participants did not know what their gross annual income was. Six individuals said that they earn over \$50,000 (two were working and four were not working). The main factor determining adequate income is usually participation in paid employment (National Health Committee, 1998). However, many of the participants in this study who were receiving ERC from ACC had similar incomes to those who were employed. There was no statistically significant correlation between employment and income ( $p > 0.05$ ). The individuals who were not working and receiving ERC from ACC featured in all of the income groups and so did the individuals who were employed.

The respondents were also asked what form(s) of income they received (Table 8.12). Many of the participants received more than one form of income. The majority of people (75.7%) were receiving ERC from ACC, followed by 31.4% who were receiving the Independence Allowance from ACC and 22.9% who were receiving either wages or a salary.

**Table 8.12 Respondents' forms of income**

Forms of Income	Frequency (n)	Percent of sample (%)
ACC Earning Related Compensation	53	75.7
ACC Independence Allowance	22	31.4
Wages / Salary	16	22.9
Self-employed / Investment Income	7	10.0
Invalids Benefit	6	8.6
Disability Allowance	6	5.7
Accommodation Supplement	4	4.3
National Superannuation - Guaranteed Retirement Income	3	2.9
Special Benefit	2	1.4
Sickness Benefit	1	1.4
Student Allowance	1	1.4
Domestic Purposes Benefit	1	1.4
Top up to the minimum wage	1	1.4
Total*	122	

\* There were 122 responses from 70 participants.

(Source: Access to employment opportunities for people with SCI Survey)

### 8.6.4 Health Status at interview

Individuals were asked how they perceived their health status when they were interviewed (Table 8.13). The majority of the respondents (61.4%) described their health status as good or excellent. Just over half of the participants (53.3%) who were not working perceived their health status as good or excellent compared to 78.2% who were working. None of the people who were employed perceived themselves as having a poor health status, in contrast to four (8.5%) of the unemployed people. So although in previous questions eighteen of the people who were not employed (38.3%) said that their health, injury and/or medical complications

were their main reasons for not working, only eleven people (23.4%) considered their health status to be below average.

**Table 8.13 Participants' self-perceived health status at interview**

Self- perceived health status	Working		Not Working		Total	
	n	%	n	%	n	%
Poor	0	0.0	4	8.5	4	5.7
Fair	3	13.0	7	14.9	10	14.3
Average	2	8.7	11	23.4	13	18.6
Good	13	56.5	19	40.4	32	45.7
Excellent	5	21.7	6	12.8	11	15.7
Total	23	100	47	100	70	100

(Source: Access to employment opportunities for people with SCI Survey)

## 8.7 Chapter Summary

This chapter has suggested that work is highly valued in our culture and is important for many reasons such as generating an income, providing social contacts and enhancing psychological well-being. It has also discussed the effects of unemployment. The people in this study who were employed when interviewed generally got a lot of satisfaction and a sense of achievement from working. Many of the individuals who were not employed when interviewed did not think there was anything positive about not working and they often missed the social contacts that work provides and found it difficult to fill in time. This chapter has also briefly looked at how the lives of the people with SCI who were interviewed have changed since sustaining their SCI.

The final chapter will summarise the main findings of this research. It will make some recommendations on how vocational rehabilitation for people with SCI in New Zealand could be improved. Future research directions, especially for geographic research on disability, will also be considered.

## **CHAPTER NINE: Conclusions & Recommendations**

### **9.1 Introduction**

SCI is a life changing event for any individual (Smith, 1999). The improved survival rates of people sustaining this injury and fewer medical complications have meant that the issue of return to work has become an important consideration in the rehabilitation process. To the best of the researcher's knowledge this is the first New Zealand study to exclusively examine the access to employment opportunities for people with SCI. Therefore, the research objectives were wide ranging in the hope that a general picture of the employment experiences for this group of people would emerge, and could be as a basis for future research.

The function of this final chapter is to revisit the objectives of this study, to summarise the main findings and shortcomings. It will make some recommendations on how vocational rehabilitation at the Burwood SIU could be improved. The same applies to the services that both ACC and Workbridge provide for people with SCI. Future research directions will also be considered.

### **9.2 Geography and Disability**

There is an emerging interest in disability issues in human geography. The lack of geographic literature on disability issues has been attributed to the absence of people with disabilities in academia and their powerlessness in society (Chouinard & Grant, 1995; Imrie, 1996a). The profile of disability issues has been raised with the increasing assertiveness among the disabled population as they have begun to organise themselves and demand equal rights and inclusion into mainstream society (Barnes, 1998; Smith, 1999). Chapter Two reviewed recent research on disability in human geography. This showed that definitions of

disability depend on the way society perceives specific disabilities and what is defined as 'disabling' is subject to change. The medical model of disability has traditionally guided disability research. For example, Golledge's (1993) positivistic research on disability is orientated towards the medical model, which sees disability as a problem within the individual. This fails to consider the wider aspects of disablement such as the social, physical and attitudinal barriers caused by society. However, more geographers have begun to use the social model of disability to examine how the spatial structure of the built environment contributes to the exclusion of people with disabilities and the way that public policy perpetuates ableist attitudes and values. Emancipatory approaches have also emerged which venture beyond characterising disability as a physical or social problem, to focus on involving disabled people in the research process, to make disability research more relevant to people with disabilities and improve their quality of life.

This thesis has encompassed the principles of the social model of disability to recognise that the nature of the built environment and negative attitudes towards disability can further disempower disabled people. Because no published New Zealand research has specifically looked at the employment issues for people with SCI, the current study used both quantitative and qualitative research methods to provide a baseline for further research. People with SCI were involved in all stages of this research. Using face-to-face in-depth semi-structured interviews enhanced the qualitative data and gave the people with SCI the chance to express their personal feelings and experiences. The research context at the Burwood SIU enabled people from a variety of locations around New Zealand to be interviewed. Although it was not possible to determine the extent to which the group interviewed was representative of the total population of people with SCI in New Zealand, the seventy people contacted nevertheless provided a broad cross section of people with traumatic SCI in terms of geographical location, demographic and injury related variables.

## **9.2 Vocational Rehabilitation for People with SCI**

This thesis set out with three major objectives. The first of these was to identify if there were any shortcomings in the current provision of vocational rehabilitation and support services for people with SCI. In order to meet this objective Chapter Four examined vocational rehabilitation within the hospital system using the Burwood SIU as a case study, and Chapter Five investigated the provision of vocational and support services for people with SCI provided by ACC and Workbridge.

### **9.2.1 Vocational Rehabilitation at the Burwood SIU**

The interviews revealed a significant lack of vocational rehabilitation at the Burwood SIU. Clearly, there is a lot more that the Burwood SIU could be doing with regard to vocational rehabilitation, so as to improve the employment outcomes of people with SCI. Vocational rehabilitation needs to become an elemental and compulsory component of the rehabilitation process at Burwood, and needs to be available to all patients and be highly publicised within the SIU. Photographs of people with SCI at work could be put up around the Burwood SIU to help inspire people and show them that life does go on. All of the staff need to be convinced of the appropriateness of addressing post-discharge occupational goals to foster a positive attitude towards employment following SCI.

There should be one person within the multi-disciplinary team of staff at Burwood who is solely responsible for meeting the diverse vocational rehabilitation needs of the people with SCI. This would ensure that vocational rehabilitation is addressed and everyone has the opportunity to discuss his or her vocational goals and options. The person responsible for vocational rehabilitation needs to have a clearly defined role and introduce themselves early on and follow up individuals on a regular basis, both before discharge and at each reassessment.



The Burwood SIU need not attempt to undertake any job placements; this is the role of organisations such as Workbridge. It would be more beneficial for the person responsible for vocational rehabilitation to help individuals identify the transferable skills that they have (especially if they are unlikely to be able to return to their previous occupations) and help people to make realistic goals. People with SCI need to take responsibility for their futures. The Learning from Experience Trust has produced a pack, entitled *Making Your Experience Count*, which encourages people to identify their personal qualities, achievements and transferable skills and it provides examples of how to present these in CVs and application forms (see, Cornell, 1997a; 1997b). Something like this could be useful to help people with SCI recognise their abilities. Individuals need to know where they can get further assistance, support and information when they return home (for example, the Disability Information and Resource Centres, DPA, and the New Zealand Spinal Trust's Spinal Network News). People also need to be made aware of the variety of opportunities for further education, training and the entitlements for assistance and help with returning to work that are provided by ACC and Workbridge.

Considering only 18.5% of the people who were interviewed in this study returned to the job that they had prior to their injury, the early introduction of vocational rehabilitation may improve the employment outcomes for this group of people. Vocational rehabilitation needs to be introduced early on in the rehabilitation process to foster a positive attitude towards returning to work after SCI and to prevent people adopting a dependency attitude. Improved information dissemination on service availability in the areas where people live is seen as the most significant factor in improving access to services as it insures that people can choose to access a service or not (Ratima et al, 1995). People need to be aware of all of their options before they leave the SIU because the smaller areas to which some individuals return to may not be able to provide specialised vocational rehabilitation assistance, to enable them to make

informed choices about the feasibility of returning to work and retraining options (Regional Rehabilitation Services Working Party, 1987).

Following SCI, many individuals have to learn new skills to (re)enter the labour market because the physical implications of this injury may impact on their ability to undertake the exact responsibilities of their previous employment (Smith, 1999). The challenge is to help people to recognise their abilities and to assist them to reach their full potential. It would be advantageous to give the individuals who have not used computers before the opportunity to learn more about them and their potential applications while they are inpatients. This could help to inspire people and overcome any fears that they may have about computers. Some of the participants in this study expressed a desire to learn more about new technology and the Burwood campus is a good place to start this learning process as part of rehabilitation.

### **9.2.2 Vocational rehabilitation for People with SCI provided by ACC**

Chapter Five examined the issue of vocational rehabilitation once people leave the hospital system. New Zealand has a unique system of accident compensation for people who suffer accidental injuries. There have been many changes and reviews of the accident compensation scheme since it came into operation in 1974. The majority of the participants (92.4%) in this study were entitled to rehabilitative care and support from ACC. The interviews revealed that ACC had not discussed vocational rehabilitation with the majority (60.1%) of these individuals. This is very surprising considering the overriding goal of ACC is to return people to work or to independence as quickly as possible (ACC, 1999b). This raises the question as to whether ACC thinks people with SCI are capable of working.

It is not cost-effective having people who sustain spinal cord injuries on ERC from ACC for the rest of their lives. If ACC spent more money on vocational rehabilitation and properly retraining people with SCI, less money would be spent by ACC in the long-term. The young age of many of the individuals sustaining traumatic spinal cord injuries indicates the long term cost-effectiveness and advantages of vocational rehabilitation and getting these people back to work. This is because "some degree of economic independence saves economic resources but also fosters psychological well-being and self-esteem" (Regional Rehabilitation Services Working Party, 1987: 4). Because ACC has a financial interest in returning people to work, helping to fund a vocational rehabilitation specialist at the Burwood SIU would have cost benefits.

Although 44% of the people in this study thought that ACC had been helpful and supportive, many participants expressed concern that ACC does not tell people what they are entitled to, the length of time it takes to get things done and the frequency of changes in case managers. There appears to be too many inequities in the support and assistance that people with SCI currently receive from ACC. To reduce some of these inequities it is imperative that the claimants of ACC know what they are entitled to and it should not be dependent on their own knowledge of entitlements determining what they receive. Perhaps ACC should provide people with SCI a list of exactly what they are entitled to from ACC. Delays in completing housing modifications and getting equipment need to be minimised because they can slow down rehabilitation and return to independence. Considering people with SCI can have complex support needs and are likely to be long-term claimants of ACC it would make practical sense to assign people to case managers who are going to be able to follow through their rehabilitation plans.

### **9.2.3 Vocational support for People with SCI provided by Workbridge**

As New Zealand's specialist employment agency for people with disabilities Workbridge's lack of involvement in getting spinal cord injured persons into employment following injury warrants serious questions. The interviews revealed that more than half of the respondents in this study (52.9%) had not heard about Workbridge and only ten individuals (14.3%) had actually used Workbridge's services. Workbridge has an easily identifiable "captive market" of clients at the Burwood SIU. However, there is no input from Workbridge at Burwood and this group of clients is ignored. Perhaps organisations such as ACC and Work and Income New Zealand (WINZ) assume that Workbridge is catering for people with SCI. But this is not the case and therefore they are being missed. It appears that this group of relatively young capable individuals is being neglected because of an institutional, personal and widespread belief that people with SCI are not capable of working. But surely this is Workbridge's job?

There is a lot that Workbridge could be doing to promote itself. For example, they could have publicity material on display around the SIU and the hostel at Burwood Hospital. Individuals should be told about the availability of Workbridge Centres in the areas where they live before they leave hospital. Workbridge should be joint funders of a vocational rehabilitation person at Burwood and their staff should also visit the SIU on a regular basis to promote awareness of their services and improve their own understanding of SCI.

## **9.3 The Rate, Type and Predictors of Employment for People with SCI**

The second objective was to establish the type, rate and predictors of employment for people with SCI in New Zealand. Work is highly valued in our culture and serves a variety of

functions. Existing literature details a diversity of return to work rates following SCI. The findings in this study are within the range of overseas studies. Chapter Six illustrates the dramatic changes in the employment status for the seventy spinal cord injured people in this study. Although 83% of the participants were employed at the time of injury, only 32.7% were employed at the time of interview. The ability of people with SCI to work is a function of a variety of factors such as age when injured, time since injury, education, labour market factors, financial disincentives, along with a range of vocational and motivational factors. The importance of these factors varies between individuals which reflects the complexity of the issue of employment following SCI.

Chapter Seven examined some of the main barriers to accessing employment opportunities, specifically from the perspective of people with SCI. The two main barriers or difficulties that the individuals who were interviewed in this study had encountered when trying to find work since their injury were accessibility issues and employers' attitudes and perceptions (both of which are in the remit of Workbridge). Over half of the participants (51.4%) had not looked for work since their injury. People's main reasons for not working were because of their injury, health, or medical complications (38.3%) and some said that were not yet physically able to work or had not finished their rehabilitation (29.8%). Yet only 23.4% of the participants perceived their health status to be below average. Although many respondents (45.7%) were very uncertain about their ability to do a full days work, and, often commented that if they did work it would have to be part-time, the majority (78.6%) said that they definitely wanted to work. This study has highlighted the fact that people with SCI are not a homogeneous group and that their capabilities, needs and the barriers that they face are not necessarily the same.

A great deal of work remains to be done, before people with SCI have equal access to employment opportunities. To overcome barriers to employment or career advancement for people with disabilities, changes need to take place in individuals attitudes, workplaces and the wider socio-political environment. One of the keys to getting disabled people into work is to change other peoples' perceptions of them through personal interaction and positive media images. The Disability Sector Vocational Coalition (1997: 5) suggests that:

Education of employers should promote people with disabilities as employees and emphasize that people with disabilities are capable, productive, reliable and (despite some needing support) need not be any more expensive to employ than non-disabled people.

It would have been good to examine non-disabled peoples' experiences of working with or employing disabled people to provide a more complete picture on the employment of people with disabilities in the New Zealand context. However, this was not a realistic option given the time constraints placed upon this study. Given the high levels of unemployment for the people in this study there is a need for more research to identify ways to overcome barriers to employment after SCI. For example, Welham (1997: 3) suggests that:

It is imperative that the issues surrounding information technology and disability be examined and understood so that steps may be taken to make the appropriate tools of information technology available to people with disabling conditions so they can take their place in, and contribute to society as equal and independent citizens.

## **9.4 Life changes after SCI**

The third objective was to explore some of the life changes after SCI and the impact of employment outcomes for spinal cord injured people on their perceived health status, social outcomes and life satisfaction. Those who sustain SCI experience a loss of choice or narrowing of options in many areas of life, including employment opportunities. Chapter Eight illustrated that work is highly valued in our culture and is important for a variety of reasons such as generating an income, providing social contacts and enhancing psychological

well-being. This study showed that those who were employed when interviewed generally received a lot of satisfaction and sense of achievement from working. Many of the individuals who were not employed when interviewed did not think there were any positive aspects about not working and they often missed the social contacts that work provides and found it difficult to fill in time.

Chapter Eight also examined how the lives of people who were interviewed had changed since sustaining their SCI. When the participants were asked about how they felt about their lives over half of the individuals (52.2%) who were working said they were happy, compared with 38.3% of those who were not working. A higher percentage of the working respondents (39.1%) said they were satisfied with their lives compared with 21.3% of those who were not employed. People often said that they felt frustrated (25.7%) because of the daily frustration associated with the ongoing physical difficulties resulting from SCI and/or the problems they were having with ACC. Five of the individuals (10.6%) who were not working said that they were depressed compared to none of those who were working. The majority of people (54.3%) said that they made less social outings since their injury mainly due to accessibility problems. There was also a significant reduction in the sports participation (62.9%) and leisure activities (47.1%) of the individuals in this study since their injury, the main reasons being the physical limitations of SCI and access difficulties. When interviewed just over half of the participants (53.3%) who were not working perceived their health status as good or excellent compared with 78.2% of those who were working.

## **9.6 Directions for future research**

This study makes a significant contribution to the literature on employment after SCI and it provides a useful basis for more in-depth research. In terms of future research, the obvious

directions for expanding and strengthening a study such as this one would be to include more subjects and have a longer follow up period. Longitudinal research would be extremely valuable to track people at different stages after injury, and allow examination of return to work rates, and changes in attitudes and expectations regarding employment following SCI over time. The way spinal cord injuries affect other family members employment status could be explored so as to investigate whether more people's partners end up going out to work or give up work to become carers. Future research could also examine people's medical records to establish if the individuals with SCI who are unemployed have a greater number of hospital readmissions and whether they stay in hospital longer when they are readmitted compared to those who are working.

Although geographers have studied many disadvantaged groups in society, people with disabilities have received insufficient attention. As Imrie (1996b: 27) recognises:

The marginal and oppressed status of people with disabilities is a significant feature of our societies yet, in comparison with the study of racial and sexual oppression, it has received little attention.

The experiences of people with disabilities deserve more consideration and their voices need to be included in the discipline of human geography. Geographic research on disability needs to promote an understanding and recognition of how such people can be prevented from participating in society due to physical barriers and negative social attitudes. Despite the longstanding interest of geographers in social, political, economic and labour processes (such as the social relations of production, and the spatial and sexual division of labour) (Johnston et al, 1994), there has been a lack of geographic research on disability and employment. This merits further exploration, for example, research could explore how the impacts of economic restructuring and the decline in the Welfare State have impacted on the labour force participation of people with disabilities. A geographic perspective on disability also needs to explore the processes underpinning the social construction of disability and examine the



causes of oppression and marginalisation of disabled people. Although geographers have looked at attitudes towards people with disabilities (see, for example, Dear et al, 1997; Butler & Bowlby, 1997) future research could specifically focus on employers' attitudes towards employing disabled people.

More geographic research is needed to explore the inter-relationships between disability, physical access and the built environment. Geographers should focus on emancipatory research methods which aim to empower disabled people and uncover perceptions of, and attitudes towards, people with disabilities in a variety of contexts. This requires sensitivity to the social relations of research production to enable disabled people's voices and experiences to be heard. Previous geographic research on disability has mainly come from the United Kingdom, the United States and Australia. Future research needs to investigate the experiences of people with disabilities in developing countries.

Disability affects a significant number of people and there is a lot more geographic research that could be undertaken on disability issues. The Disability Surveys carried out by Statistics New Zealand in 1996 (the Household Disability Survey) and 1997 (Disability Survey of Residential Facilities) provided the first national, population based data on disability in New Zealand. A joint publication by the Ministry of Health and the Health Funding Authority (HFA) in 1998 entitled *Disability in New Zealand* provides detailed statistical analysis on these surveys, which shows that there were 702,000 people with disabilities. As the New Zealand population ages more people are likely to experience disability, as the risk of disability increases with age (Katzehellenbogen, 1998). *Disability Counts*, a Statistics New Zealand (1998) study using the 1996 Census data and information from the 1996/97 Disability Surveys, found that disability rates are higher in the South Island (24%) than in the North Island (16%). The reasons for the high rate of disability in the South Island are not

clear, but are thought to be related to selective in-or-out migration (Katzehellenbogen, 1998). There is scope for geographers to explore the reasons for the spatial variations in the prevalence of disability in New Zealand. Access to support and services for people with disabilities is another area of research which merits further consideration, especially for those in rural areas.

## **9.7 Conclusion**

In conclusion, this study has provided a range of information on the access to employment opportunities for people with SCI. The shortcomings in the vocational rehabilitation and support services for spinal cord injured people which are provided by the Burwood SIU, ACC and Workbridge have been identified. Recommendations have been made to improve the provision of vocational rehabilitation and support services for this group of people to enhance their employment outcomes. Areas for future research have also been described. Geographers need to continue 'making space for difference' (Kearns, 1995) to ensure that the voices of people with disabilities are included in more areas of future geographic research.

This thesis has illustrated that the nature of employment after SCI is complex and multifaceted. The concerns and difficulties that these people experience when they return to work after their injury have been highlighted in an attempt to improve the understanding of SCI, and recognise the abilities and ambitions that these individuals do have. The message is not how awful life is for these people or how wonderful they all are. As one person said; "we don't want everyone's sympathy just their understanding." There are many occupations which are suitable (or can be made suitable with the right support and/or resources) for people with SCI. The challenge is for the Burwood SIU, ACC and Workbridge to work

together and assist these individuals to lead productive lives that they are capable of and to ensure that they all realise their full potential in all spheres of life.

## GLOSSARY

- Activities of Daily Living (ADL)** Such as eating, drinking, grooming, dressing, writing, and handling objects eg telephones and books. Nurses, occupational therapists and physiotherapists are the main educators of ADL.
- Acute** The early stages of an injury (as opposed to chronic which is long term).
- Acute Care** Includes evacuation and transport, emergency and early medical care.
- Assistive Technology** Devices that can eliminate, ameliorate or compensate for functional limitations
- Calliper** Metal support for weak or injured leg.
- Catheter** A flexible rubber or plastic tube used for withdrawing or introducing fluids into a cavity of the body, usually the bladder.
- Central Nervous System (CNS)** The CNS includes the brain and the spinal cord.
- Cervical** The upper spine (neck) area of the vertebral column.
- Complete Injury** No sensory or motor function below the level of injury.
- Elective Procedure** A procedure such as tendon transfer surgery that is not acute and can be booked according to the person's relative priority.
- Employment** Any activity undertaken for financial reward.
- FES (Functional Electric Stimulation)** The application of computer-controlled electric current to paralysed muscles to enhance or produce function such as walking and hand control.
- Incomplete Injury** Some sensation or motor control below the level of injury is preserved as some nerve pathways remain intact.
- Incontinence** Lack of bowel and/or bladder control.
- Intermittent Catheterisation** Using a catheter for emptying the bladder on a regular schedule as needed. The catheter is not left in the bladder.
- Lumbar** The strongest part of the spine pertaining to the area below the thoracic spine.
- Motor function** The use of the body's extremities such as legs and arms.

<b>Pressure Sore</b>	Also known as a decubitus ulcer. Skin breakdown due to excessive pressure on the skin, which interferes with blood flow and results in infection and tissue death. They are preventable and very expensive to treat.
<b>Paralysis</b>	Loss of motor or sensory function of nerves
<b>Paraplegia</b>	Loss of function below the cervical spinal cord segments, the upper body usually retains most function and sensation.
<b>Quadriplegic</b>	The American term for tetraplegic
<b>Rehabilitation</b>	A sequence of services designed to restore optimum physical, psychological, social and vocational levels of function.
<b>Sacral</b>	Refers to the fused segments of the lower vertebrae or lowest spinal cord segments below the lumbar level.
<b>Sensory Function</b>	The ability to feel pleasure or pain and heat or cold.
<b>Tertiary Services</b>	Specialised high tech services that are usually high cost and low volume services provided in national or regional centres rather than by all hospitals.
<b>Tetraplegia</b>	Paralysis affecting all four limbs, resulting from damage to the cervical spine.
<b>Thoracic</b>	Pertaining to the chest, vertebrae or spinal cord segments between the cervical and lumbar areas.
<b>Urology</b>	The branch of medicine and surgery concerned with the urinary tract.
<b>Ventilator</b>	A mechanical device to facilitate breathing in people with impaired diaphragm function.
<b>Vertebrae</b>	The bones which make up the spinal column and protect the spinal cord.
<b>Vocational Rehabilitation</b>	A process of assisting individuals to manage their occupational future.
<b>Work</b>	Unlike employment, work may be undertaken on a voluntary basis, without financial reward.

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## Appendix A: Spinal Cord Injury Terminology

Spinal cord injury is damage to the spinal cord that results in a loss of motor and sensory function. The human spinal cord is made up of many neurons and is protected by thirty-three vertebrae, which together are known as the spinal column. The four main sections of spinal column (Appendix B) are; the cervical (neck), thoracic (trunk), lumbar and sacral (at the base of the spine) (Sherrard, 1996; Spinal Cord Injury Resource Center, no date; Clay's Spinal Cord Injury Page, no date). The region and the number of the vertebrae classify the level of injury to the spinal cord. For example, C-7 refers to injury at the level of the seventh cervical vertebrae (Morris, 1989). The higher the level of injury to the spinal cord, the greater the area of loss of sensation and/or movement to the upper body. (Seymour, 1998). In this study the participants' injury levels ranged between C3 and L5. The level of cord injury also predicts what parts of the body might be affected by paralysis (Appendix B). The bowel, bladder and sexual organs are affected by most spinal cord injuries because the nerve supply to these organs comes from the lower end of the spinal cord (Rodgers, 1986). The most common spinal cord injuries occur at the spine's areas of greatest flexibility, which are the mid to low cervical level of C5-6, followed by the connection of the thoracic and lumbar nerves at T12-L1 (Corbet et al, 1998).

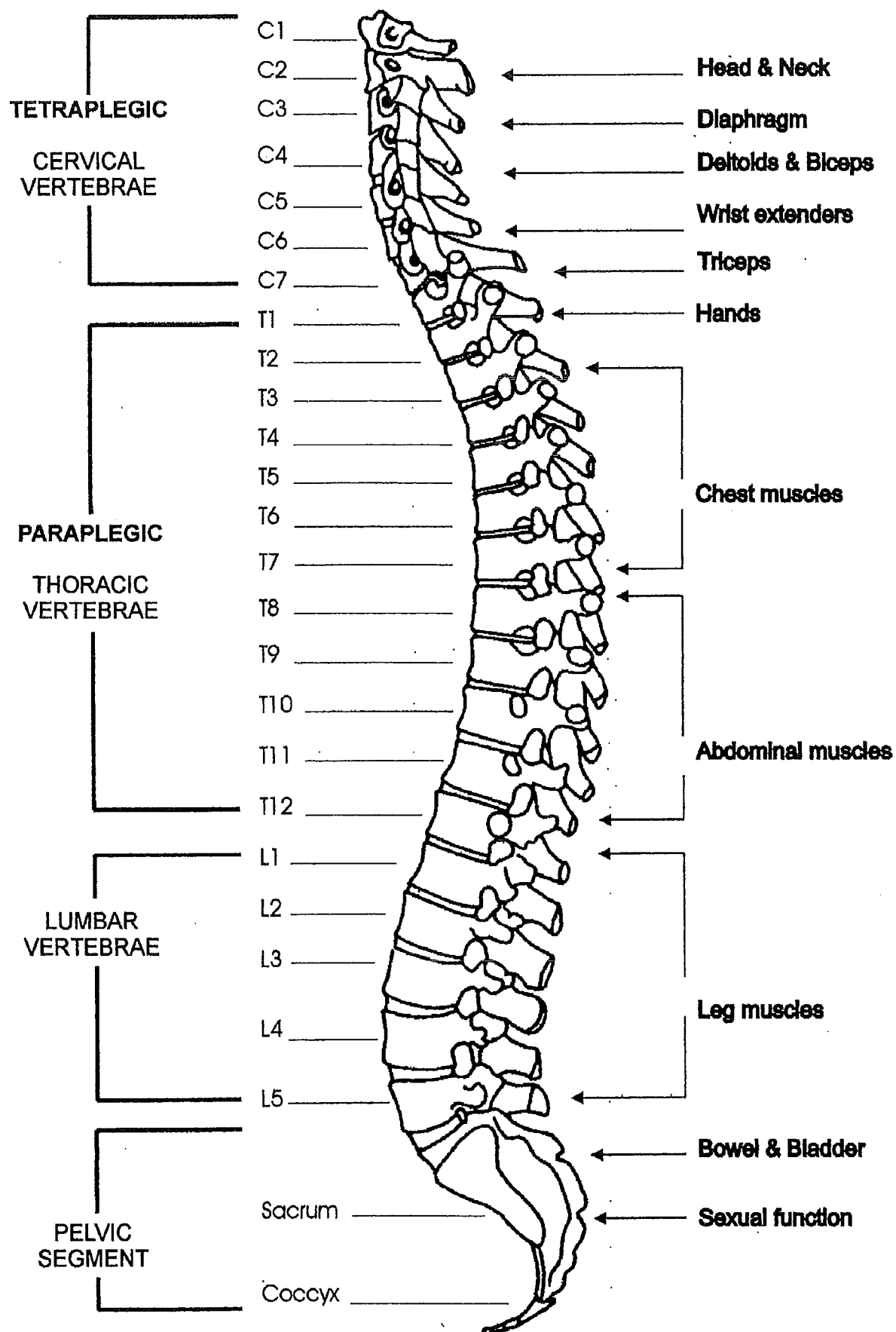
Spinal cord injuries are either complete or incomplete. A *complete* injury means that both sides of the body are equally affected and there is total loss of motor and sensory function below the level of injury. Whereas an *incomplete* injury means that, there can be some functioning below the level of the injury. This is because some of the nerve pathways in the spinal cord still exist at the injury site. A person with an incomplete SCI may be able to move one limb more than another, may be able to feel parts of the body that cannot be moved, or may have more functioning on one side of the body than the other. Two people may have the

same level of injury, but different degrees of completeness; consequently one person may have more function than the other. Every incomplete SCI is therefore, different and unique (Morris, 1989; Minchington & Julian, 1989; Spinal Cord Injury Resource Center, no date; Clay's Spinal Cord Injury Page, no date).

*Paraplegia* refers to damage to the spinal cord at the thoracic or lumbar level. Paraplegics can have loss of motor and sensory function from the chest down, again depending on the level of injury and whether it is complete or incomplete (Morris, 1989; Sherrard, 1996) *Tetraplegia* (the American term is quadriplegia) refers to damage to the spinal cord in the cervical region. This involves loss of motor and sensory function in the upper the body (including the arms and hands) as well as the legs and trunk (Morris, 1989; Minchington & Julian, 1989). If a person's injury is above the fourth cervical vertebrae, they are usually dependent on a ventilator to breathe (Sherrard, 1996; Cure Paralysis Now, 1997).

Not all people who sustain spinal cord injuries have to use wheelchairs for mobility. Some people are able to walk (sometimes callipers and/or braces are needed) although this does not mean that they will never use a wheelchair. Many people who use callipers and/or braces to assist their walking sometimes find wheelchairs useful for longer distances and for practicality around home or if they are fatigued. People with high cervical level injuries often use power wheelchairs. While people with spinal cord injuries at the lower cervical level and below usually use manual wheelchairs (Spinal Cord Injury Resource Center, no date; Clay's Spinal Cord Injury Page, no date).

## Appendix B: Map of the Spinal Column



(Source: adapted from Barron's Educational Series, 1997 & Spinal Cord Resource Page, no date)

## **Appendix C: List of people who were consulted for this research**

<b>Manu Sione</b>	Christchurch Manager at Workbridge	15 January 1999
<b>Mark Turner</b>	Ph.D. Student researching Pain and SCI	19 January 1999
<b>Bronwyn Thompson</b>	Pain Management Centre Burwood Hospital	18 March 1999
<b>Karen Wilson</b>	Clinical Nurse Specialist Burwood SIU	1 April 1999
<b>Gill Fowler</b>	Disabilities Co-ordinator University of Canterbury	5 May 1999
<b>Sharon Mackenzie</b>	Occupational Therapist Burwood Hospital	13 May 1999
<b>Glenn Barnes</b>	Case Manager Christchurch ACC	13 May 1999
<b>Steve Lavery</b>	Marketing Manager at Workbridge	9&10 June 1999
<b>Professor Alan Clarke</b>	Clinical Director Burwood SIU	numerous occasions
<b>Graham Tapper</b>	Administration Manager Burwood SIU	numerous occasions
<b>Kate Hirst</b>	Editor of Spinal Network News	numerous occasions



## Appendix D: Copy of the Questionnaire used in this study

Interview No. \_\_\_\_\_ Date: \_\_\_\_\_ Location: \_\_\_\_\_ Duration: \_\_\_\_\_ to \_\_\_\_\_

**QUESTIONNAIRE:**  
**ACCESS TO EMPLOYMENT OPPORTUNITIES FOR PEOPLE WITH SCI**

### SECTION A: INTRODUCTION

**Q.1** How old were you when you were injured? \_\_\_\_\_ **Years**

**Q.2** How long ago were you injured? \_\_\_\_\_ **Months** \_\_\_\_\_ **Years**

**Q.3** What was the cause of your injury?

- ☐ Motor Vehicle Accident
- ☐ Fall
- ☐ Sport / Recreation (Please specify) \_\_\_\_\_
- ☐ Work Accident \_\_\_\_\_
- ☐ Other (Please specify) \_\_\_\_\_

**Q.4** What level is your injury? (eg T-9) \_\_\_\_\_

- ☐ Incomplete
- ☐ Complete

**Q.5** Are you a wheelchair user? \_\_\_\_\_

### SECTION B: WORKFORCE PARTICIPATION BEFORE YOUR INJURY

**Q.6** What was your employment status before your injury?

- ☐ Employed Full-time
- ☐ Employed 20 hours or less per week
- ☐ Student
- ☐ Full-time homemaker and / or parent
- ☐ Unemployed and seeking work
- ☐ Not working and not seeking employment
- ☐ Retired
- ☐ Other (Please specify) \_\_\_\_\_

**Q.7** What was the highest educational qualification you gained before your injury?

- ☐ None
- ☐ School Certificate
- ☐ Sixth Form Certificate
- ☐ Bursary
- ☐ Certificate or Diploma
- ☐ Trade Certificate
- ☐ University Undergraduate Degree
- ☐ University Postgraduate Degree
- ☐ Other (Please specify) \_\_\_\_\_

**Q.8** If you were employed before you were injured, what was your occupation?  
(Please specify) \_\_\_\_\_

**Q.9** How long had you been working for prior to your injury? \_\_ Years \_\_ Months

**Q.10** Please describe any other occupation(s) that you had before your injury...

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### **SECTION C: VOCATIONAL & SUPPORT SERVICES FOR PEOPLE WITH SCI**

**Q.11** What vocational rehabilitation (if any) did you have while you were at the Burwood Spinal Injuries Unit? (Please comment) \_\_\_\_\_

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**Q.12** How satisfied were you with the vocational rehabilitation you received at Burwood? (Please comment) \_\_\_\_\_

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**Q.13** Have you ever received help from ACC?

☐ No **GO TO Q.16**

☐ Yes

**Q.14** What vocational help & guidance (if any) have you had from ACC?

(Please comment) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Q.15** How satisfied were you with the vocational support you received from ACC?

(Please comment) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Q.16** Do you know about Workbridge and what it does?

☐ No **GO TO Q.20**

☐ Yes

**Q.17** How did you find out about Workbridge? \_\_\_\_\_

**Q.18** Have you ever used Workbridge's services?

☐ No **GO TO Q.20**

☐ Yes

**Q.19** How satisfied were you with the service you received from Workbridge?

(Please comment) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Q.20** Have you received any of the following? **Tick any that you have received**

☐ Job Support

☐ Training Support

☐ Self-Start (for setting up a business)

**Q.21** Please describe any other vocational support you have received that has not been mentioned so far...(eg from Work & Income NZ) \_\_\_\_\_

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#### **SECTION D: GAINING EMPLOYMENT AFTER YOUR INJURY**

**Q.22** Have you experienced and / or thought about any of the following issues with regard to employment? **Tick one on each line**

	Never	A Little	A Lot
A. There are no jobs out there	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Concern about losing entitlement to ACC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Uncertain about ability to do a full days work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Not having confidence to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. My doctor said that I cannot go back to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F. Lacking the skills and qualifications to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G. Afraid of reinjury or harming myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H. Not wanting to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I. Worry about bowel and bladder control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J. Having to work for financial security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q.23** Have you done any further education or training since your injury?

☐ No

☐ Yes - What you have done? \_\_\_\_\_

**Q.24** Would you like to do some further education or training in the future?

☐ No

☐ Yes

☐ Don't Know

**Q.25** Do you have access to the Internet?

☐ No

☐ Yes

**Q.26** What sort of computer skills do you have?

- ☐ None
- ☐ Very Limited
- ☐ Average
- ☐ Good
- ☐ Excellent

**Q.27** Please describe what occupations (if any) you have had since your injury....

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**Q.28** Have you done any voluntary work since your injury?

- ☐ No
- ☐ Yes

**Q.29** What is your employment status now?

- ☐ Employed Full-time – How many hours per week? \_\_\_\_\_
- ☐ Employed Part-time – How many hours per week? \_\_\_\_\_
- ☐ Voluntary Work - How many hours per week? \_\_\_\_\_
- ☐ Student – Is that part-time or full-time? \_\_\_\_\_ **GO TO Q.42**
- ☐ Full-time homemaker and / or parent **GO TO Q.42**
- ☐ Unemployed and seeking work **GO TO Q.42**
- ☐ Not working and not seeking employment **GO TO Q.42**
- ☐ Retired **GO TO Q.48**
- ☐ Other (Please specify) \_\_\_\_\_

**Q.30** Would you prefer to work more hours per week than you currently work at present? (Please comment) \_\_\_\_\_

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**SECTION E: YOUR WORKPLACE**

**Q.31** What is your current occupation? \_\_\_\_\_

**Q.32** How long have you been working in your current job? \_\_\_\_ **Years** \_\_\_\_ **Months**

**Q.33** How did you get your current job?

- ☐ Worked there prior to injury
- ☐ Through a friend or personal contact
- ☐ Through a Newspaper Advertisement
- ☐ Own application directly to an employer
- ☐ Workbridge Placement
- ☐ Other (Please specify) \_\_\_\_\_

**Q.34** What sort of difficulties or barriers did you encounter when you tried to find work after your injury? (Please comment) \_\_\_\_\_

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**Q.35** What is your usual method of getting to and from work?

- ☐ Work From Home
- ☐ Private Car or Van
- ☐ Taxi (Using vouchers form the Total Mobility Scheme)
- ☐ Bus / Public Transport
- ☐ Other (Please specify) \_\_\_\_\_

**Q.36** Approximately how long does it take you to travel to work? \_\_\_\_\_ **Minutes**

**Q.37** Did your current workplace require any modifications, to improve its' accessibility? (Please comment) \_\_\_\_\_

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**Q.38** Did your current workplace require any special equipment for you to do the job? (Please comment) \_\_\_\_\_

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**Q.39** Does your current job require you to use all of your skills and abilities? (Please comment) \_\_\_\_\_

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**Q.40** How do you feel about your career advancement & promotion prospects? (Please comment) \_\_\_\_\_

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**Q.41** Does your job give you a sense of satisfaction & achievement? (Please comment) \_\_\_\_\_

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**GO TO Q.48**

#### **SECTION F: BEING UNEMPLOYED**

**Q.42** What are your main reasons for not working? (Please comment)

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**Q.43** What do you find difficult about being unemployed? (Please comment)

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**Q.44** Are there any good things about being unemployed? (Please comment)

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**Q.45** How long have you been out of work for? \_\_\_\_\_ **Years** \_\_\_\_\_ **Months**

**Q.46** What sort of difficulties or barriers have you encountered when trying to find work since your injury? (Please comment) \_\_\_\_\_

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**Q.47** What do you see standing in the way of you getting a job at the moment?

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### **SECTION G: BACKGROUND INFORMATION**

Finally here are some questions which will help to find out more about the characteristics of the people taking part in this survey.

**Q.48** Are you...

- ☐ Male
- ☐ Female

**Q.49** Which one of the following best describes your ethnic background?

- ☐ New Zealand European
- ☐ New Zealand Maori
- ☐ Pacific Islander
- ☐ Asian
- ☐ Other (Please specify) \_\_\_\_\_

**Q.50** Which of the following best describes your current household situation...

- ☐ Living alone
- ☐ Living with flatmates
- ☐ Living with partner
- ☐ Living with partner and children
- ☐ Living with parent(s)
- ☐ Other (Please specify) \_\_\_\_\_



**Q.51** Where in New Zealand do you currently live? \_\_\_\_\_

**Q.52** What was your marital status before you were injured?

- ☐ Single
- ☐ Married
- ☐ De-facto
- ☐ Divorced or Separated
- ☐ Widowed

**Q.53** What is your marital status now?

- ☐ Single **GO TO Q.55**
- ☐ Married
- ☐ De-facto
- ☐ Divorced or Separated
- ☐ Widowed

**Q.54** Does your partner or spouse work?

- ☐ Yes – How many hours per week? \_\_\_\_\_
- ☐ No - Does not work
- ☐ Other (Please specify) \_\_\_\_\_

**Q.55** Compared with the way your life was before your spinal cord injury, how are these things for you now? **Tick one on each line**

	More	About the Same	Less
Number of friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contact with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social outings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sports participation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q.56** Which of these words best describes how you currently feel about your life?  
**Tick as many as you like**

- |  |                                      |
|--|--------------------------------------|
| <input type="checkbox"/> Happy           | <input type="checkbox"/> Frustrated  |
| <input type="checkbox"/> Satisfied       | <input type="checkbox"/> Mostly OK   |
| <input type="checkbox"/> Not Coping Well | <input type="checkbox"/> Up and Down |
| <input type="checkbox"/> Depressed       | <input type="checkbox"/> Unhappy     |

**Q.57** Can you use your transportation independently?

- ☐ Yes  
☐ No

**Q.58** Does your usual method of transport allow you to get out when you want?

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**Q.59** How do you perceive your general health?

- ☐ Poor  
☐ Fair  
☐ Average  
☐ Good  
☐ Excellent

**Q.60** Do you experience any chronic pain related to your Spinal Cord Injury?

- ☐ No **GO TO Q.62**  
☐ Yes – How would you describe the pain?

- ☐ Mild  
☐ Moderate  
☐ Severe

**Q.61** Does this pain affect your ability to work? (Please comment)

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**Q.62** What form(s) of income do you currently receive? **Tick all that you receive**

- ☐ Wages / Salary
- ☐ Self employed / Business Investment Income
- ☐ ACC Earnings Related Compensation
- ☐ ACC Independence Allowance
- ☐ Invalids Benefit
- ☐ Disability Allowance
- ☐ National Superannuation – Guaranteed Retirement Income
- ☐ Student Allowance
- ☐ Accommodation Supplement
- ☐ Other (Please specify) \_\_\_\_\_

**Q.63** What was the total income that you personally received, before tax in 1998?

- ☐ Less than \$10,000
- ☐ \$10,001 to \$15,000
- ☐ \$15,001 to \$20,000
- ☐ \$20,001 to \$25,000
- ☐ \$25,001 to \$30,000
- ☐ \$30,001 to \$40,000
- ☐ \$40,001 to \$50,000
- ☐ More than \$50,000

**Q.64** Are you a member of the Spinal Network of the New Zealand Spinal Trust?

- ☐ No
- ☐ Yes

**THANK-YOU VERY MUCH FOR YOUR TIME AND EFFORT**



## Appendix E: Information Sheet



Department of Geography

University of Canterbury Private Bag 4800  
Christchurch New Zealand  
Telephone: 03-366 7001  
Fax: 03-364 2907

### INFORMATION SHEET

You are invited to take part in the research project **“Access to Employment Opportunities for People with Spinal Cord Injuries”**. This research is important because there is very little New Zealand information on the employment experiences of People with SCI.

The aim of this research is to find out more about the employment experiences of People with SCI in New Zealand. The primary purposes of this research are:

1. To identify the rates, types and predictors of employment for People with SCI.
2. To identify any shortcomings in the current provision of vocational rehabilitation and support services for People with Spinal Cord Injuries.
3. To explore the impact of employment outcomes on perceived health status, social outcomes and life satisfaction.

Your involvement in the project will involve one interview, which should take about 30 minutes. I want to talk to People with Spinal Cord Injuries from a wide range of backgrounds including both employed and unemployed people.

If you take part in this study, you have the choice to refuse to answer any particular question and to withdraw from the study at any time. The information that you provide is on the understanding that it is completely confidential. The results of the project may be published but it will not be possible to identify you, as you are not asked to put your name or any other identifying information on the questionnaire.

The project is being carried out for the purpose of a Masters Thesis and is being supervised by Doctor Ross Barnett. The University of Canterbury Human Ethics Committee has approved this project. It also has the support of Professor Alan Clarke, the Clinical Director of the Burwood Spinal Injuries Unit.

If you have any questions or concerns about your participation in this research project, please do not hesitate to contact me at the University of Canterbury 366 7001 ext 8078 or at home 355 8109.

Yours sincerely,

A handwritten signature in cursive script, reading 'Jane Robertson'.

JANE ROBERTSON

## **Appendix F: Consent form**

### **CONSENT FORM**

#### **Access to Employment Opportunities for People with SCI**

I have read and understood the description of the above-named research project. On this basis I agree to participate as a subject in the project, and I consent to the publication of the results of the project with the understanding that anonymity will be preserved. I also understand that I may at any time withdraw from the research, including the withdrawal of any information I have provided.

Signed \_\_\_\_\_

Date \_\_\_\_\_

## **Appendix G: New Zealand Standard Classifications of Occupations (NZSCO 95)**

1. **LEGISLATORS, ADMINISTRATORS AND MANAGERS**  
Legislators, Administrators and Corporate Managers
2. **PROFESSIONALS**  
Physical, Mathematical and Engineering Science Professionals  
Life Science and Health Professionals  
Teaching Professionals and other professionals
3. **TECHNICIANS AND ASSOCIATE PROFESSIONALS**  
Physical Science and Engineering Associate Professionals  
Life Science and Health Associate Professionals  
Other Associate Professionals
4. **CLERKS**  
Office Clerks and Customer Service Clerks
5. **SERVICE AND SALES WORKERS**  
Personal and Protective Services Workers  
Salespersons, Demonstrators and Models
6. **AGRICULTURAL AND FISHERIES WORKERS**  
Market Orientated Agricultural and Fisheries Workers
7. **TRADE WORKERS**  
Building Trades Workers  
Metal and Machinery Trades Workers  
Precision Trades Workers  
Other Craft and Related Trades Workers
8. **PLANT AND MACHINE OPERATORS AND ASSEMBLERS**  
Industrial Plant Operators  
Stationary Machine Operators and Assemblers  
Drivers and Mobile Machinery Operators  
Building and Related Workers
9. **ELEMENTARY OCCUPATIONS**  
Labourers and related Elementary Service Workers

(Source: Statistics New Zealand, 1995)